Exploring the application of Inclusive Design to the improvement of healthcare services

Yuanyuan Liu

Downing College
Department of Engineering
University of Cambridge

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ABSTRACT

An ageing population is demanding more of healthcare services worldwide, particularly for long-term conditions. In the UK, the challenge of limited healthcare service resources and the influence of the Equality Act on services have increasingly led to the consideration of people's access to community rehabilitation services. These present a potential opportunity for Inclusive Design. The literature suggests that Inclusive Design and its associated tools have been widely applied to the accessibility of buildings and public transport, as well as consumer products and services, but there is little evidence of their application to healthcare services.

A review of the literature highlights the importance of improving people's access to community-based rehabilitation by providing care at or closer to home which has become an increasingly prevalent option to meet the healthcare demand for long-term conditions in an ageing population. Therefore, this thesis investigates how Inclusive Design can be applied to healthcare delivery services to improve patients' experiences of accessing these services. It accomplished this through two case studies: community-based rehabilitation services of back pain and chronic obstructive pulmonary disease (COPD). The case studies involved online surveys and interviews with healthcare professionals and patients in understanding the patients' care journeys and challenges in accessing these services. The impact of services demands on patients' capability and their access to services was analysed using an Inclusive Design tool, the Exclusion Calculator. An inclusive approach integrating tools and procedures was summarised to facilitate the understanding of patients' capability-related needs both for the recipients of care and for the providers of care.

This research provides a novel contribution by filling the gaps in the literature on the application of Inclusive Design to healthcare delivery services, i.e., community-based

rehabilitation. It demonstrates that an Inclusive Design approach can be used to improve people's access to healthcare services and the tools applied can make a useful contribution to understanding service provision and hence service improvement. The Inclusive Design approach focuses on identifying the demands that healthcare services make of their users' capability and in estimating services' exclusion. The process of applying Inclusive Design in this research may be used to improve other healthcare services.

DECLARATION

This thesis is my own work and contains nothing which is the outcome of work done in collaboration with others, except as specified in the text and acknowledgements. References to work developed by other researchers are explicitly indicated in the text.

No part of this thesis has been submitted in whole or in part as consideration for any other degree or qualification at this University or any other Institute of Learning.

It does not exceed 65,000 words, including appendices, references and tables, and does not contain more than 150 figures.

Some of the work contained in this dissertation has been published and presented as below:

Y. Liu, T. Dickerson, F. Early, J. Fuld, P. J. Clarkson. Understanding influences on the uptake of pulmonary rehabilitation in the East of England: an Inclusive Design / mixed-methods study protocol. BMJ Open 2018;8:e020750. doi:10.1136/bmjopen-2017-020750.

Y. Liu, T. Dickerson, S. D. Waller, P. Waddingham and P. J. Clarkson. The role of Inclusive Design in improving people's access to treatment for back pain. Breaking Down Barriers: Usability, Accessibility, and Inclusive Design (Part IV – P195-206). Springer International Publishing 2018.

Yuanyuan Liu

Downing College
University of Cambridge
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Table of Contents

List of figures

List of tables

List of abbreviations

CCG: Clinical Commissioning Groups

CLAHRC: Collaboration for Leadership in Applied Health Research & Care

COPD: Chronic Obstructive Pulmonary Disease

CUH: Cambridge University Hospital, UK

CRN: Clinical Research Network

DFS: Disability Follow-up to the Family Resources Survey

DRM: Design Research Methodology

EDC: Engineering Design Centre

EoE: East of England

HCP: Healthcare Professional

HRA: Health Research Authority

NHS: National Health Service, UK

NICE: National Institute for Health and Care Excellence, UK

PR: Pulmonary rehabilitation

RSA: Royal Society for the encouragement of Arts, Manufactures and Commerce

Terminology

NHS: The UK's National Health Service (NHS) includes both primary and secondary care.

NHS Trust: An NHS Trust is an Organisation to provide goods and services for the purposes of the health service. NHS Trusts may act as healthcare providers and provide hospital services, community services and other aspects of patient care, such as patient transport facilities. They may also act as commissioners when sub-contracting patient care services to other providers of health care.

Health and care vs Healthcare: The term "*health and care*" refers to health and social care, which include all the health and social care, such as public health and community service. The term "*healthcare*" means a system, industry, or field that facilitates the logistics and delivery of health care for patients/consumers. In this research, the term "*healthcare*" is used, which refers to community-based care services.

Primary care: Primary care is the first point of contact for most people and is delivered by a wide range of independent contractors, including general practitioners (GPs), dentists, pharmacists and optometrists.

Secondary care: It means being taken care of by someone who has particular expertise in whatever problem a patient is having. Secondary care services are usually based in a hospital or clinic. It is where most people go when they have a health problem that can't be dealt with in primary care because it needs more specialised knowledge, skill or equipment than the GP has. The GP will decide what kind of specialist the patient needs to see and contact them on the patient's behalf to get them an appointment – this is called a 'referral'.

Community-based care: refers to those care services offered in, or closer to, people's homes, within and across 'primary care'(NHS) and social care settings.

Code: A descriptive or conceptual label that is assigned to excerpts of raw data in a process called 'coding.'

Lay summary: A brief summary of a research project that is used to explain complex ideas and technical terms to the general audience. It is useful in supporting wider public engagement with research, in particular for research in medicine and health.

1 Introduction

This chapter presents an overview of the motivations that drive this research and the resulting research questions and scope. It explains the academic contributions and the impact of the work. Finally, a brief summary of each chapter is given as a map for the thesis.

1.1 Research motivations

- **Ageing population**

In 2017, the global population aged 60 and over was 962 million and the number of older persons was expected to double by 2050, reaching nearly 2.1 billion and accounting for 20% of the whole population. The number of people aged 80 and over was projected to increase more than threefold between 2017 and 2050, rising from 137 million to 425 million globally (United Nations, 2017). In the UK, the population continues to age, and the proportion of the population aged 65 and over reached 18.0% in mid-2016 (Office for National Statistics, 2017a). As shown in Figure 1.1, it is estimated that the potential support ratio (i.e., the number of people age 15-64 for every person aged 65 and over) in the UK will drop steadily from 4.2 in 1999 to about 2.45 by 2040 (Shaw, 2001).

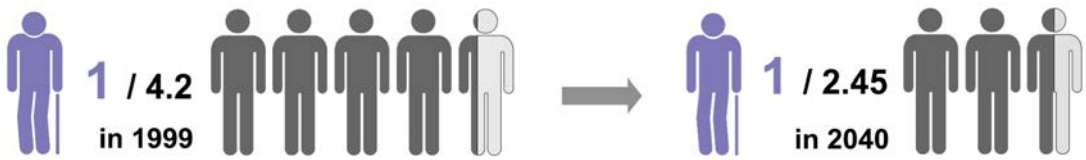


Figure 1.1 The potential support ratio from 1999 to 2040 in the UK

- **Challenges of healthcare services**

The increased age of the population will result in a higher demand on healthcare services. According to Her Majesty's (HM) Government (2012), more than eight out of 10 people aged 65 and over will need some care and support in their later years. Almost 5 million people in England currently care for a friend or relative, some for more than 50 hours per week.

In England, about 15 million people have a long-term condition and they constitute the largest healthcare users, 50% of all GP appointments and 70% of inpatient bed days. In total, 70% of the healthcare budget is used for the care of people with long-term conditions. As a result, 30% of the population accounts for 70% of the healthcare services' spending. Older people are also more likely to suffer from long-term conditions, while 58% of those aged 60 and over report

having one long-term condition, and 25% of over 60s report two or more long-term conditions (Department of Health, 2012a).

A long-term condition is one that can only be controlled by medication or therapy and cannot be cured at present. People with long-term conditions typically do not want to be in hospital unless it is absolutely necessary, and they want support to understand their condition and confidence to manage their care (Department of Health, 2012a).

- **The need for improving the utilisation of community-based healthcare service**

Community-based care aims to provide care closer to people's homes and thus helps to avoid unnecessary hospital admission (Edwards, 2014; Mapstone, 2000). It is the increasingly preferred means of providing care for most people with longer term and mild to moderate conditions as it enables people to keep their normal routine, staying close to family and friends (The NHS Constitution, 2013). More importantly, promoting community-based care could possibly curb the growth in emergency admissions, for which the total cost over is £13.5 billion a year (Department of Health, 2012a). One community care provider in Cambridgeshire and Peterborough estimated, "if nothing were done to change community-based care, it is predicted that in five years' time the number of older people admitted to hospital would grow by 31%: we would need the equivalent of a new hospital to cope" (UnitingCare Partnership, 2015). Therefore, it is necessary to enhance the utilisation of community-based healthcare services.

- **People's capabilities**

People's capabilities can be categorised into sensory abilities (vision and hearing), motor abilities (mobility, dexterity, and reach & stretch) and cognitive abilities (communication and thinking) (Martin *et al*., 1988, Clarkson *et al*., 2007, Schifferstein and Hekkert, 2008). People's capability level can be affected by both nature and nurture factors. Some people are born with reduced capability (disability). The two main nurture factors that cause a change in people's capability are age-related capability change and condition-related capability change. Specifically, compared to younger adults, older people may have a lower level of capability such as declined hearing and vision. This capability loss may consequently lead to a higher demand of older people on products and services. Also, people's capabilities may change due to their physical conditions. For example, patients with COPD are likely to have limited mobility causing them not be able to walk for a long distance as their condition may make them feel breathless. Therefore, it is important to take people's capabilities into consideration when

improving healthcare services, since access is a prerequisite for people to make use of these healthcare services.

- **Inclusive Design**

Inclusive Design can be defined as: i) "the design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible without the need for special adaptation or specialised design" (British Standards Institute, 2005); and, from a more pragmatic perspective, as: ii) ensuring that the demand made on an individual in a given environment does not exceed their capability to respond (Clarkson and Coleman 2013). In this study, Inclusive Design refers to the latter definition.

The Inclusive Design approach is a rigorous user-centred approach, where the fundamental premise is that accessible and usable products or services can only be developed or implemented by first knowing the intended users. By understanding the user's capability-demand in a healthcare context, it is easier to understand their capability-related needs for care and enhance the implementation of healthcare services.

The challenges associated with healthcare service delivery in an ageing population create a potential research opportunity for Inclusive Design, namely how to improve people's access to healthcare services by understanding the services' demand on people's capability. This triggered the research questions.

1.2 Research questions and scope

The objective of this thesis is to produce evidence of how Inclusive Design can be applied to healthcare services and to demonstrate what the value is of applying Inclusive Design in understanding people's access to healthcare. In order to achieve this objective, the following overarching research question is explored:

How can Inclusive Design be used to improve access to healthcare services in the community?

The question is answered through a series of individual research questions:

What are the challenges?

- Sub-RQ1 What is the state-of-the-art understanding and application of Inclusive Design?

- Sub-RQ2 What are the challenges of an ageing population associated with community-based healthcare service delivery?
- Sub-RQ3 To what extent do people's capabilities affect their access to community-based healthcare services?

How do we make it better?

- Sub-RQ4 How can we use the principle of Inclusive Design to improve people's access along the care journey?

In order to narrow the research scope, it was important to limit the care journeys to be explored. An initial study identified patients' rehabilitation journeys in the community. Two case studies concerning community-based rehabilitation services of back pain and chronic obstructive pulmonary disease (COPD) were conducted to provide evidence to answer the sub-RQ3, RQ4 and RQ5.

- Sub-RQ5 What are the advantages and limitations of Inclusive Design as a means of improving people's access to healthcare services in the community?

1.3 The academic contributions

This research constitutes the first study in the application of Inclusive Design to specific healthcare delivery services, although Inclusive Design has been widely applied in relation to consumer products to understand customer diversity and respond to this diversity with informed design decisions. The main contributions of this research are:

i) Evidence of how Inclusive Design can be used in improving healthcare services.

ii) A summary of an inclusive approach to healthcare service design that helps healthcare providers, researchers, and even patients to understand, assess and improve healthcare services through better balancing the services' demands and the patients' capabilities.

iii) Evidence of the advantages and limitations of Inclusive Design in improving healthcare delivery.

1.4 The impact of the research

The research has the potential to impact on the following three areas:

a) Individuals and society:

To improve access to community-based healthcare services for people with long-term conditions and assist them in better self-managing their conditions, particularly those people with reduced capabilities who may not have been able to access these healthcare services before. The research supports the equal access of the UK Equality Act 2010 which emphasises the importance of preventing the inequality of access to services.

b) Healthcare services and government recourses:

To offer more inclusive community-based rehabilitation services to patients with long-term conditions and reduce the number of hospital admissions by improving the accessibility of these healthcare services; to raise healthcare providers' awareness to patients' capability-related needs and use an inclusive approach to improve the design of other healthcare services. Moreover, this research could help the government save a large amount of the healthcare budget and resources used for people with long-term conditions every year.

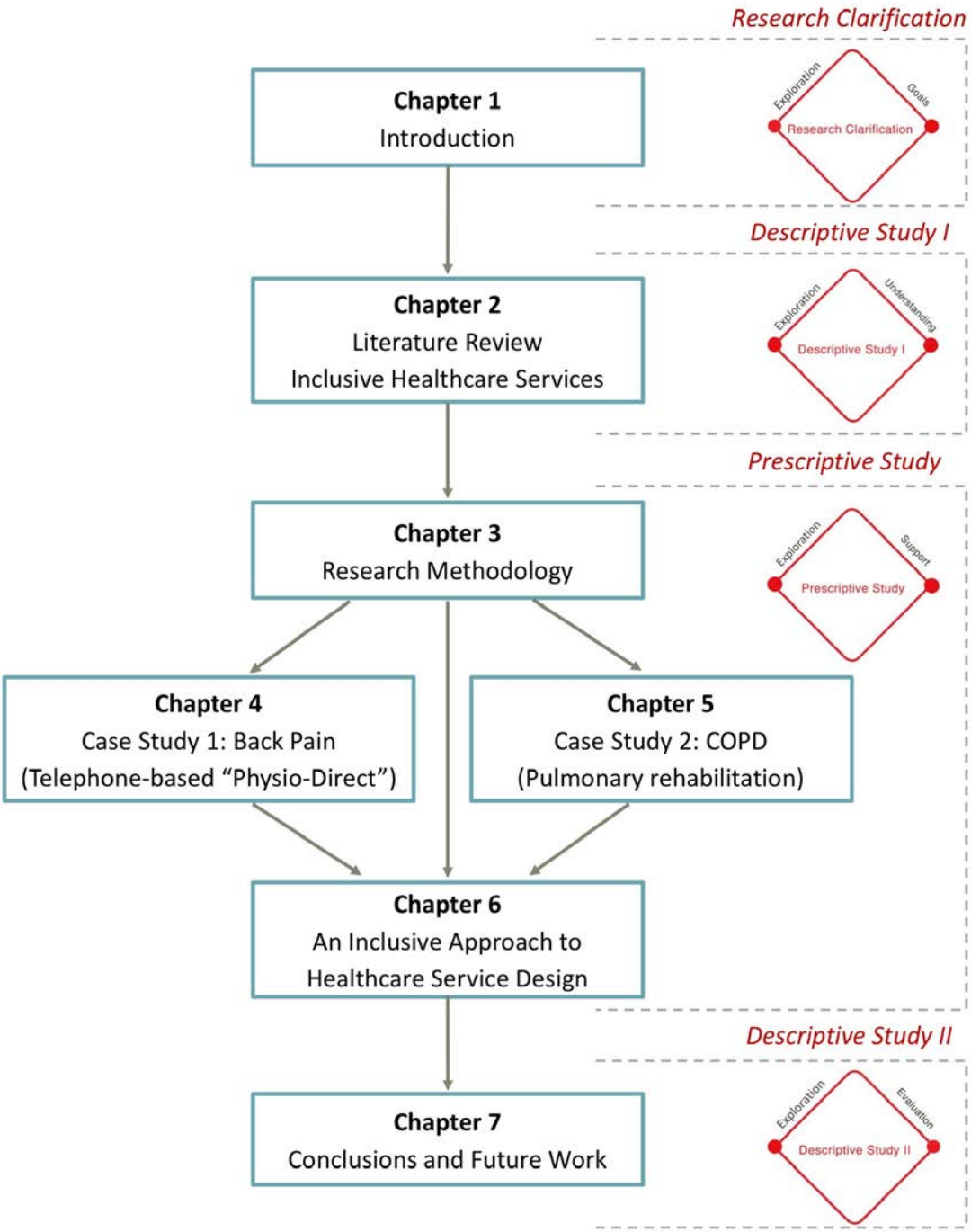
c) Research：

To create knowledge of design research in the healthcare industry and provide a foundation for researchers to develop and disseminate a useful design approach in the healthcare industry, as well as to suggest additional directions of further development and investigation.

1.5 Thesis structure

The structure of this thesis is presented in Figure 1.2, which demonstrates the relationships between each chapter. Two case studies of community-based rehabilitation services related to back pain and chronic obstructive pulmonary disease (COPD) are used to explore an inclusive healthcare approach.

Figure 1.2 The structure of the thesis



A summary of the seven chapters are presented below:

Chapter 1, 'Introduction': provides a brief overview of the research motivations; a description of the research questions and scope; the contributions and potential impact of the research, and a map of the thesis structure.

Chapter 2, Literature Review: 'Inclusive healthcare service in the community' (sub-RQ1, RQ2 and RQ3): describes the concept and scope of Inclusive Design, clarifies the need for community-based healthcare, and describes the requirement to understand patients' needs along their care journey.

Chapter 3, 'Research Methodology': explains how a research methodology has been designed based on a critical review of different research methodologies, and describes the path taken to address the research questions.

Chapter 4, 'Applying Inclusive Design to improve community-based back pain self-management' (sub-RQ3, RQ4, RQ5): describes an online questionnaire survey and interview with healthcare professionals (HCPs) to gather insight into their experiences of delivering back pain care; describes how to use people's personal care stories online and patients' feedback to gather insight into their experiences of managing their back pain; explains the challenges caused by access to suitable back pain care for individuals and estimates how many people might not be able to access the care service; proposes recommendations that aim to address challenges of patients, improve their access to the" Physio-Direct" service and thus help them better self-manage their back pain.

Chapter 5, 'Applying Inclusive Design to improve utilisation of community-based pulmonary rehabilitation(PR)' (sub-RQ3, RQ4, RQ5): identifies and compares COPD care pathways of HCPs and care journeys of patients through semi-structured interviews; describes the challenges caused by access to PR and estimates how many people might not be able to access the service; proposes recommendations for a "*Your COPD care Reminder*" which can help patients manage their COPD care, informed by addressing the challenges and refined through a survey with HCPs and focus groups with patients.

Chapter 6, 'Reflections on the Inclusive Approach to Healthcare Service Design' (sub-RQ5): summarises an inclusive approach to healthcare service design based upon the research process and findings from Chapter 5 and Chapter 6.

Chapter 7, 'Conclusions and further work': summarises the research and proposes future work.

2 Literature Review: Inclusive Healthcare Services

2.1 Review structure

This chapter summarises and critiques relevant research and identifies gaps in the field. Table 2.1 is an indicative list of academic databases, reports from health research organisations, prominent authors' publications, new editions of relevant journals and conference proceedings which were consulted to provide evidence for the research questions. Key terms and synonyms such as *accessibility* and *capability* were searched. The main criteria for selecting a review source was whether it was about Inclusive Design, healthcare services and patients, and relevant to the topics in Figure 2.1.

Table 2.1 The indicative list of literature review sources

Category	Name
Academic databases	e.g., Web of Science, Scopus, PubMed, Google scholar, NHS evidence, CINAHI
Health research organisations	e.g., Kings Fund, Health Foundation, IHI, British Lung Foundation
Authors' publications	e.g., Clarkson P. J., Coleman R., Keates S., Dong H., Lebbon C., Bichard J., Cassim J.
Journal	e.g., Applied Ergonomics, the Journal of Engineering Design, Design studies
Conference proceeding	e.g., Include, ICED, CWUAAT

The review contains various areas of research as a result of the main research question:

How can Inclusive Design be used to improve access to healthcare services in the community?

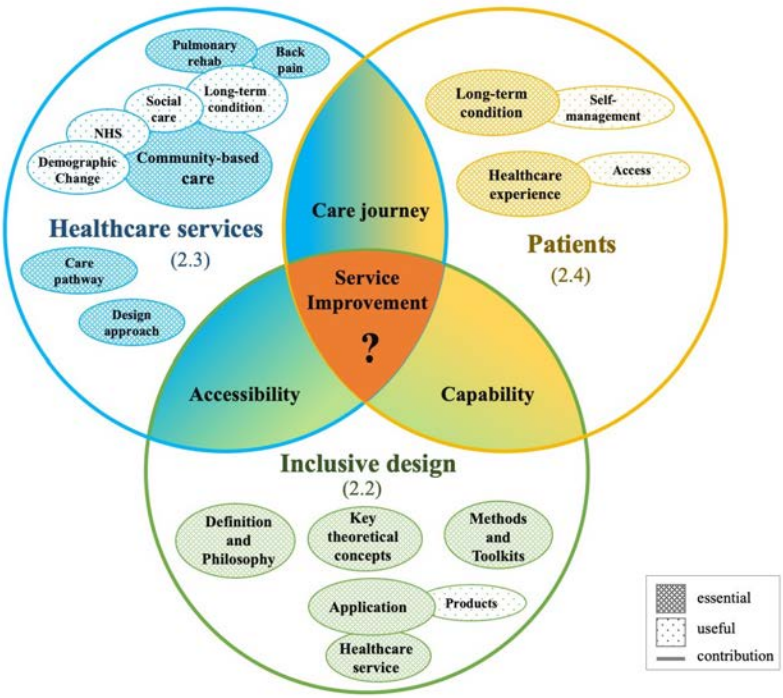


Figure 2.1 Outline of literature supporting the research

Specifically, the overarching research question focuses on Inclusive Design; the literature review presents an overview of the current state of Inclusive Design and its uptake in industry (Section 2.2). The question focuses specifically on the healthcare services industry, so the review discusses the needs of community-based care, Inclusive healthcare services, and other design approaches to healthcare services (Section 2.3). The research question also focuses on the service users, i.e., patients. Therefore, the interview review includes people's capability, healthcare experience and self-management of long-term conditions (Section 2.4). Figure 2.1 provides a summary, and the numbers in brackets refer to the sections in this chapter. The review excludes social and psychological exclusion and only focuses on physical and cognitive exclusion.

2.2 Inclusive Design (sub-question 1)

This section addresses the sub-question 1: *What is the state-of-the-art understanding and application of Inclusive Design?* Inclusive Design's definition and philosophy, key theoretical concepts, methods and toolkits, as well as industry application are discussed below (Figure 2.2).

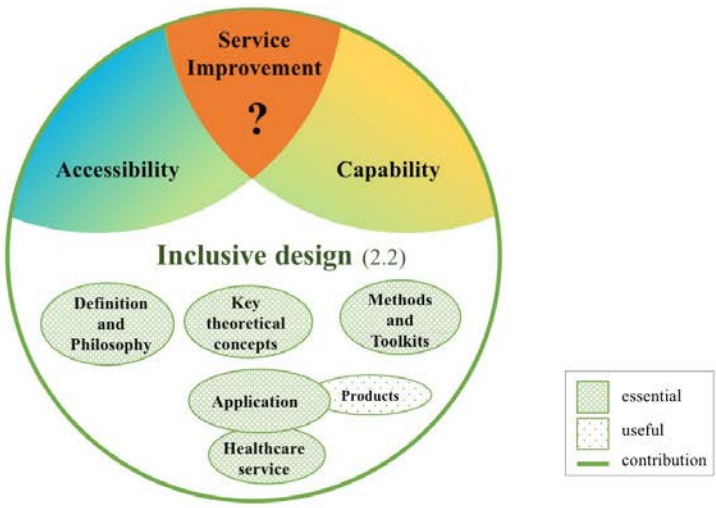


Figure 2.2 Outline of literature review on Inclusive Design

2.2.1 Definition and philosophy

Inclusive Design is "*design of mainstream products and/or services that are accessible to, and usable by, people with the widest range of abilities within the widest range of situations without the need for special adaptation or design*" (British Standards Institute, 2005). Formulated slightly differently, Inclusive Design refers to '*a general approach to designing in which*

designers ensure that their products and services address the needs of the widest possible audience, irrespective of age or ability' (Design Council, 2008).

Inclusive Design emerged in the UK and the term 'Inclusive Design' was first used in 1994 by Coleman in a conference paper (Coleman, 1994) to categorise various precedents over three prior decades, such as Designing for the Disabled (Goldsmith, 1963) and New design for old (Manley, 1986). Later, a series of policies such as the Disability Discrimination Act 1995 and the UK Equality Act 2010 prompted the development of Inclusive Design. Inclusive Design has progressively shifted from 'a medical model where people were seen as disabled by their physical and mental limitations or impairments – based on having been born with or acquired disability – to a social model in which people have disability thrust upon them by inadequate design, inconsiderate services, environments and cultural stereotypes' (Clarkson and Coleman, 2015). In short, disability could arise from both inheritance which may be unchangeable and interactions with the surrounding environment which could possibly be changeable.

The Inclusive Design approach is a user-centred approach to design (Keates and Clarkson, 2003), which means knowing the intended users is the key and prerequisite for developing accessible and usable products and services. In contrast to this, Norman (2005), a famous advocator in user-centred design, pointed out his concern that Human-Centred Design could be considered harmful. He explained that the focus on individual people could result in design catering to specific user groups and that too much attention to the users' need could lead to a lack of cohesion and add complexity. Instead, Norman suggests that an activity-centred approach to design may be beneficial, since activities involve people, and if the system supports activities it must also support the users who perform them.

Overcoming the criticism of Norman, Inclusive Design is not just about user-centred or activity-centred design. It also aims to understand how users interact with products or services (activities) within an environment in order to meet their needs (users). It is concerned not only with an individual's needs but also aims to accommodate the whole population, excluding the fewest people possible.

Other similar terms such as "Universal Design" and "Design for All" are sometimes used interchangeably with Inclusive Design. Specifically, Universal Design originated in the USA and has been adopted by Japan and the Pacific Rim. It incorporates a two-level approach: a) User-Aware Design: pushing the boundaries of 'mainstream' products, services and environments to include as many people as possible; and b) Customisable Design: design to

minimise the difficulties of adaptation to particular users. Seven principles of Universal Design were put forward by the Center for Universal Design, at NCSU to guide the design of the environment, products and communications (the details can be seen in Table 2). Design for All, which is closely related to Inclusive Design, is mainly used in continental Europe and Scandinavia. It is about ensuring that environments, products, services and interfaces work for people of all ages and abilities in different situations and under various circumstances.

Table 2.2 The Seven Principles of Universal Design (The Center for Universal Design, 1997)

Principles of Universal Design	
Principle 1: Equitable Use	the design is useful and marketable to people with diverse abilities.
Principle 2: Flexibility in Use	the design accommodates a wide range of individual preferences and abilities.
Principle 3: Simple and Intuitive Use	use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
Principle 4: Perceptible Information	the design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
Principle 5: Tolerance for Error	the design minimizes hazards and the adverse consequences of accidental or unintended actions.
Principle 6: Low Physical Effort	the design can be used efficiently and comfortably and with a minimum of fatigue.
Principle 7: Size and Space for Approach and Use	appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

In fact, all three terms have a similar purpose, i.e., a more inclusive environment for everyone, although they have different origins and are used in various parts of the world. Some researchers have suggested that the specific terminology (e.g., Inclusive Design) may disappear in the future. Instead, designing for diversity might become an inherent part of design thinking and Inclusive Design will be a design approach that aims to design for a more sustainable environment. The more designers approach diversity as valuable and normal, the more it will become part of design methodologies and general design attitudes (Herssens, 2013). The differences between terms are not the focus of this thesis.

As stated in Chapter 1 (p3), the term ‘Inclusive Design’ in this thesis refers to its more pragmatic description, i.e., ensuring that the demand made on individuals in a given environment does not exceed their capability to respond. This principle considers the capability demands that products or services and the built environment place on the users. According to the level of capability demanded by a product or service, it is possible to estimate which part of the product or service enables or disables potential users (Clarkson and Coleman, 2015).

2.2.2 Key theoretical concepts of Inclusive Design

2.2.2.1 The User Pyramid

Benktzon (1993) first used *the user pyramid approach* to understand the range of users' capabilities and thus develop new products in Sweden (Figure 2.3).

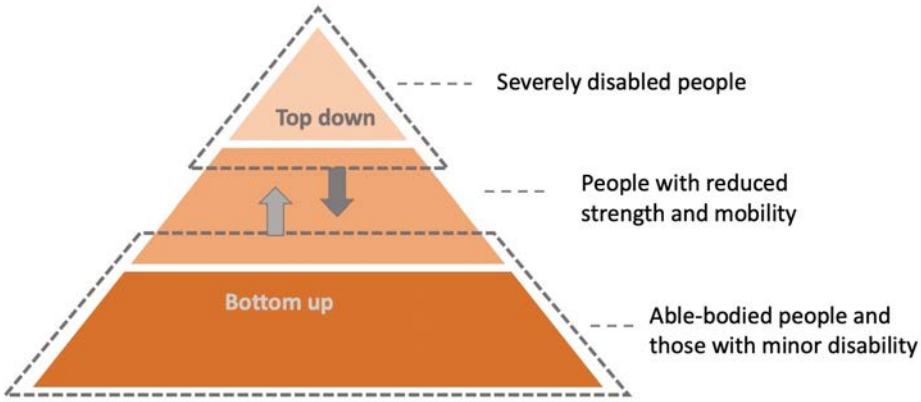


Figure 2.3 The user pyramid approach to Inclusive Design

The user pyramid consists of three levels: a) the lower level of the pyramid shows people who are able bodied or have minor capability loss; b) the middle level represents people with reduced strength and mobility due to disease and age-related impairment; c) the top level refers to severely disabled people who are unable to perform daily activities without help (Benktzon,1993).

In terms of how to use this pyramid to guide design inclusively, it could be approached from both bottom up and top down. The bottom up approach aims to design mainstream products or services to meet the needs of able-bodied people and be more inclusive, which may only go a limited distance up the pyramid, while the top down approach aims to design for the least functionally capable users (those with severe impairments) and focuses on more mainstream-friendly products. Although the top-down approach may be too specialised and optimised for a small user group and fails to be transferable to other populations, it is the key to creating truly Inclusive Design solutions (Keates and Clarkson, 2003). In fact, the user pyramid is dynamic because people may shift from the able-bodied level to the reduced capability level as result of various factors such age and diseases. In a sense, the bottom up and top down approaches complement each other to meet the needs of the whole population. This also supports the notion that Inclusive Design means designing for the whole population.

2.2.2.2 The Inclusive Design Cube

In order to understand users on the level of the whole population, the user pyramid (on the left in Figure 2.4) extends into a model called the Inclusive Design Cube by Clarkson and Keates (Clarkson and Keates, 2003). The cube contains three capability dimensions which more fully represent the whole population and three related design approaches which when being combined can address the needs of the whole population (Clarkson and Coleman, 2013).

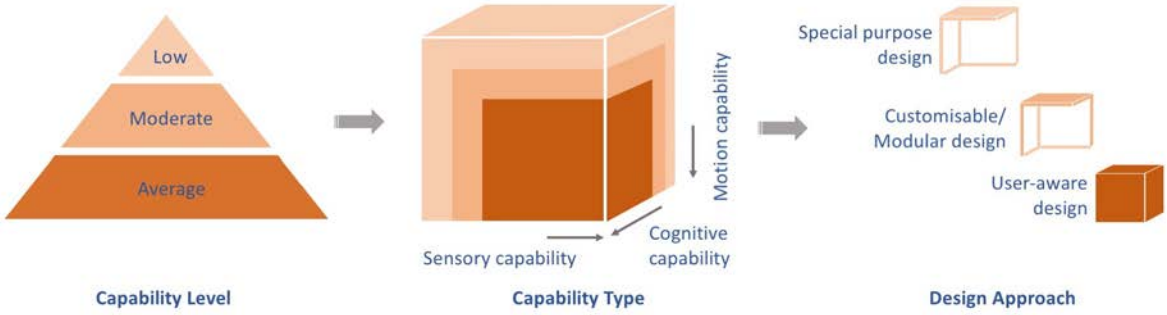


Figure 2.4 The Inclusive Design Cube (Keates and Clarkson,2003)

Specifically, the three axes of the cube represent the user's sensory, cognitive and motor capability while the enclosed volumes reflect the capabilities of the whole population. This model was adapted from the Model Human Processor (Card, Moran and Newell, 1983), one of the most practical user models depicting the perceptual, cognitive, and motor functions involved in interaction. The cube also illustrates three fundamental categories of the design approach for the whole population: a) user-aware design: pushing the boundaries of 'mainstream' products to include as many people as possible; b) customisable/modular design: designing to minimise the difficulties of adaptation to particular users; c) special purpose design: designing for specific users with very particular needs. These three approaches can be combined to provide complete population coverage.

2.2.2.3 Design Exclusion and countering Design Exclusion

Products and services can be regarded as placing demands on sensory, cognitive and motor capabilities of the user population by setting demand levels on the three axes of the cube (Clarkson *et al*., 2003). This inspires another important theory of Inclusive Design, Design Exclusion, which arises when the demand for using a particular product or service, within a given environment, exceeds the capabilities of the user (see Figure 2.5). Put simply:

If Product or Service's Demand > Users' Capability ——> Exclusion.

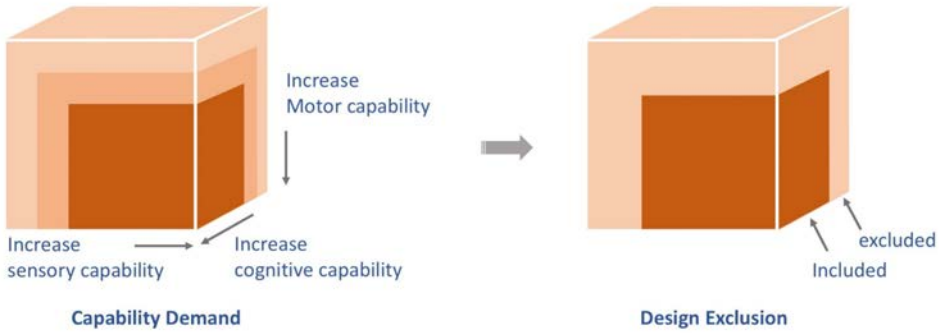


Figure 2.5 Design Exclusion is shown through the Inclusive Design Cube (Clarkson *et al*., 2003)

The concept Design Exclusion is particularly useful because identifying why and how end-users cannot access or readily use a product or service enables users to take steps to counter such exclusion. This is because knowing who and how many people cannot use the products or the services highlights the aspects of the products and services that could be improved and thus possibly include more users. Specifically, by identifying the capability demands placed upon the users by the features of the product or service, it is possible to know the end users who cannot use this product or service, irrespective of the cause of their functional impairment. Therefore, if we re-design the product or service that lessens the capability demand, a wider range of users are more likely to be included and fewer people are likely to be excluded due to inappropriate design (Clarkson *et al.*, 2003).

2.2.3 Methods and toolkits

There are various methods and toolkits which have been developed to promote Inclusive Design. Table 2.3 shows some of the representative methods and toolkits of Inclusive Design, which originated from other disciplines and areas such as *The SPROC Model* (Business) and *Task Analysis* (Behaviour and Cognition).

Table 2.3 The list of methods and toolkits for Inclusive Design

Category	Tool	Aims of the Tool or Method
Standard and Guidelines	BS 7000-6:2005. Design management systems. Managing inclusive design	BS 7000-6 provides the guidelines for adoption of inclusive approach to design of products (British Standards Institute, 2005).
Theoretical Models	The Design Wheel	To show the specific Inclusive Design activities within the 'Manage', 'Explore', 'Create' and 'Evaluate' phases of the design process (Waller *et al.*, 2015).
	The Proposed Usability, Safety, and Attractiveness Participatory (USAP) Design Model	To cooperate with the elderly to design and develop safe and functionally appropriate products that will promote and maintain independent living of them (Demirbilek, 1999).

Table 2.3 lists of methods and toolkits for Inclusive Design (continued)

Theoretical Models	The SPROC (Strategy, Process, Resources, Organisation, and Culture) Model	To "represent the elements of a business that can have an impact on its ability to implement Inclusive Design" (Clarkson *et al*., 2007).
Toolkits and Resource Packages	Inclusive Design Mapping Tool ("Petals & Flowers")	To rethink of the user states and contexts tool (Treviranus, 2016)
	Inclusive: A Microsoft design toolkit	To retrofit to design team's goals: practice new skills, develop new concepts, or create a prototype. The toolkit is a comprehensive resource for any inclusive session people want to lead (Microsoft, 2015).
	Design with People -20 Methods	To help designers engage with people during the design process (Helen Hamlyn Centre for Design, 2010).
	Inclusive Design Toolkit	To "explain what Inclusive Design is, why it is worthwhile and how to do it." And provide guidance and tools on each of these questions (Clarkson *et al*., 2007).
	The RSA Inclusive Design Resource	To draw together key contextual case studies and information about Inclusive Design including examples of products, services, buildings, business practice and inspirational design concepts. (Nicolle *et al*., 2005).
Evaluation Tool	Exclusion Calculations* (Exclusion Calculator)	To estimate the proportion of the British population who would be unable to use a product or service because of the demands it places on the users' capabilities (Clarkson *et al*., 2007).
	Expert Appraisal	To evaluate a product or service by someone who has the professional training or experience to make an informed judgement on the design (Keates and Clarkson, 2003).
	User Trials	To identify usability problems and it is commonly used in design practice with limited samples (Cardoso *et al*., 2005).
	Capability Loss Simulation* (Stimulation Gloves and Glasses; Impartment Stimulator Software)	To help designers empathise with those who have capability losses, increase their understanding of the different losses, and simulate how exclusion occurs during product interaction(Clarkson *et al*., 2007).
Aided tool	Persona**	To show archetypal users of products and services (Helen Hamlyn Centre for Design, 2010).
	Scenario**	To explore how people might interact with a particular design or context of use (Helen Hamlyn Centre for Design, 2010).
	Task analysis	To assist in the elaboration of requirements, or when evaluating the capability requirements for an existing product or service.

2.2.4 Application of Inclusive Design

Inclusive Design and its associated tools have been widely used in improving the accessibility of buildings and public transport, as well as in a range of businesses and industries to meet various people's needs including people with impairments, and to achieve business success (Clarkson *et al.*, 2003; Coleman *et al.*, 2007).

In 1971, the link between buildings' accessibility and disabled people's lives was

* It is a tool of Inclusive Design Toolkits.

** It is a tool of Design with People-20 Methods

acknowledged by the first UK legislation. The landmark British Standard (BS) 8300 was published in 2001, which offers best practice guidance on making buildings accessible and welcoming to disabled people. It is called the bible of Inclusive Design as it offers comprehensive design solutions for a whole range of disabled access scenarios (RIBA, 2016). Inclusive access is also at the heart of the Planning Policy Guidance 13: Transport (Department for Communities and Local Government, 2001), which emphasises the needs of disabled people as public transport users. The application of Inclusive Design in building's accessibility and transport indicate there is a potential chance for the application of Inclusive Design in other areas such as healthcare services.

Inclusive Design has also been applied to consumer products to meet the needs of people with impairments and include more users. In the early stages, a successful representative and well-known example was the *British Telecommunications'* (BT) embedded Inclusive Design process through their work with the design consultant company *The Alloy* to develop the cordless phone: BT Freestyle 7xx series (Warburton, Desbarats and Hosking, 2013). Sales increased by 20% after its launch in July 2008. Other case studies include the *Oxo* Good Grips' range of kitchen equipment, the *Factorydesign*'s Wares saucepan and Ferrari Enzo car (see Figure 2.6).

Figure 2.6 Case studies of Inclusive Design in products

In recent years, the Inclusive Design philosophy has been gradually applied to services to improve customers' experience and promote commercial sustainable development. For

example, the *Royal Mail Group*, an organisation employing over 200,000 people providing mail delivery, financial and retail services to the UK population, strives to accommodate the needs of its large customer and employee populations. Its Post Offices provide shops within reasonable access based upon real population data and extend to a wider range of services such as pensions and government services. Moreover, the frontline workers are invited to work together with experts in order to make the workplace both safer and more accessible. In this way, the Royal Mail Group is trying to reshape and renew its business for an ageing population (Clarkson *et al.*, 2003).

Recently, with the development of Mobile e-commerce, Inclusive Design has played an important role in designing clearer pack images which enable customers to quickly spot key information about a product, such as size, type or flavour. The new type of online product image, known as 'mobile ready hero images', can help improve the online shopping experience of customers especially older consumers with age-related long-sightedness (The global Language of Business, 2018). In addition, Inclusive Design toolkits have also been adopted in education to equip teachers to help students learn how to "Design Our Tomorrow (DOT)" (Designing Our Tomorrow, 2018).

In terms of the application of Inclusive Design to healthcare, many cases have been related to the packing and labelling of medicine, medical devices, equipment, and hospitals' environmental design (Ward, Buckle and Clarkson, 2010; Alexander *et al.*, 2001; Hignett, 2012). There is little evidence of research that applies Inclusive Design to healthcare services. One study did apply the principle of Inclusive Design to the assessment of patients' experience (Beniuk, Ward and Clarkson, 2011). The research focused on external factors that affect patients' experience, particularly the stage leading to an NHS appointment. The author argued that if it were possible to improve patients' experience before contact with the NHS, patients' could be in a better state of mind and would be able to better access services. However, the study focused on applying Inclusive Design to accessing secondary care and was not linked to any disease. In addition, it emphasised the significant need for improved care at home in its future work. Therefore, how Inclusive Design and its associated tools could be used to improve the access of specific healthcare services, i.e., community-based rehabilitation, needs to be further investigated.

To summarise Section 2.2, the literature review regarding Inclusive Design has identified a research gap, which could also be a new opportunity to show how Inclusive Design could be applied to healthcare services.

2.3 Healthcare services (sub-question 2)

This section addresses the sub-question 2: *What are the challenges of an ageing population associated with community-based healthcare service delivery?* Three related topics are explored (see Figure 2.7), i.e., the demand for and necessity of community-based care for an ageing population (Section 2.3.1), the connection between Inclusive Design and accessibility to healthcare (Section 2.3.2), and the care pathway of healthcare services (Section 2.3.3). In addition, besides Inclusive Design, the application of other design approaches to healthcare services is reviewed and discussed (Section 2.3.4).

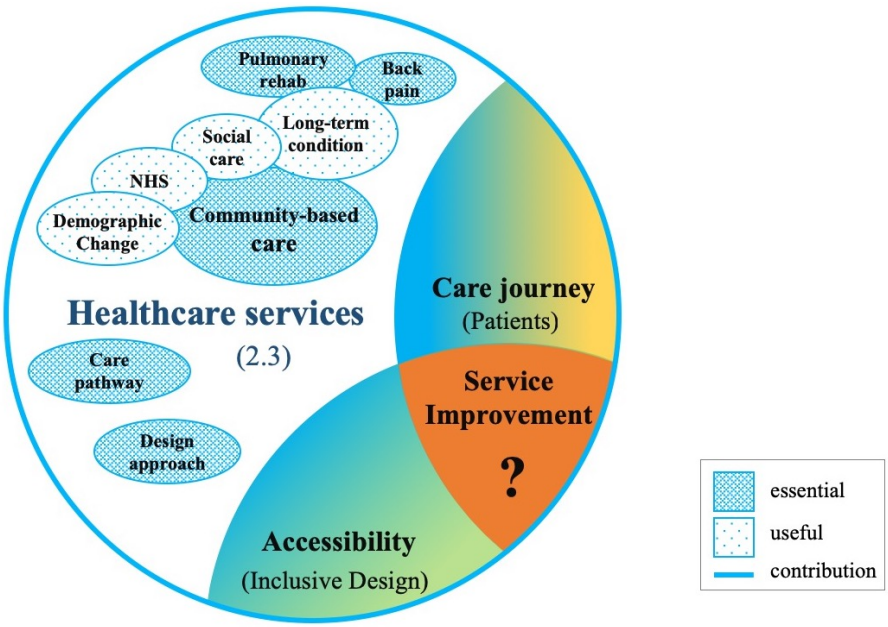


Figure 2.7 Outline of literature review on healthcare services

2.3.1 The need of community-based care

2.3.1.1 Background

An ageing population increases the demand on all health services and, in particular, the care for long-term conditions.

- The Impact of Demographic Change

The population in the UK is getting older with 18% aged 65 and over and 2.4% aged 85 and over (Office for National Statistics, 2017b). Older people are more likely to require more health services, so an ageing population has also led to the increased use of services. According to the Nuffield Trust, more than two-fifths of national health spending in the UK is devoted to people over 65, a figure that is only likely to increase with the nation's ageing demographic (Robineau, 2016). The average 65-year-old costs the NHS 2.5 times more than the average 30-year-old

and an 85-year-old costs more than five times as much (Luchinskaya, Simpson and Stoye, 2017). Witnessing the increasing demand on healthcare, it is important to understand how the general health services are organised and funded in the UK.

- The National Health Service

The main healthcare provider in the UK is the National Health Service (NHS), which was launched in 1948. It was established from a long-held ideal that good healthcare should be available to all regardless of wealth (The NHS, 2016). To some extent, this concept coincides with the Inclusive Design philosophy, i.e., products or services are designed to include as many people as possible. Following the Health and Social Care Act 2012, the NHS in England was radically changed in April 2013. The old primary care trusts (PCTs) were replaced by clinical commissioning groups (CCGs), which were designed to respond to the healthcare service needs of their local populations (see Figure 2.8). This has shown that the NHS tends to provide more specific healthcare services to local people and pay more attention to care in the community.

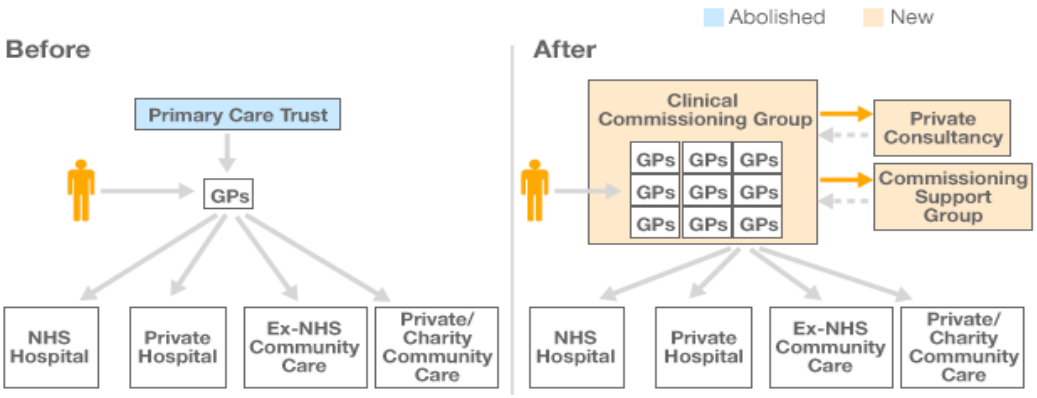


Figure 2.8 CCGs take over PCTs to charge local health services (BBC News, 2013)

Meanwhile, the NHS in England at that time was still in the middle stage of the biggest reorganisation since its creation. In the long term, the NHS may look very different and thus it may be difficult to clearly define healthcare providers' boundaries during this transition period, but for the moment patients visiting their GP or going into hospital may see little visible difference (BBC News, 2013). Therefore, this research is focused on the interaction between patients and different healthcare professionals, and only those healthcare providers with whom patients have direct contact, such as GP surgeries and community services providers.

Figure 2.9 presents the services commissioned by CCGs. It includes community services and rehabilitative services which are related to this research. The detailed NHS structure can be found in Appendix A.

Figure 2.9 CCGs' s commissioned services

In terms of funding, NHS England (2017a) received around £116.4 billion a year from the Department of Health (2015/16) and 69.5 billion was assigned to CCGs. After adjusting for the ageing of the population, per-capita real spending will be lower by 2019/20 than in 2009/10. An additional £1.3 billion would be required by 2019/20 from the of Department of Health in order to maintain 2009-10 levels of care (Luchinskaya, Simpson and Stoye, 2017).

- Social Care

Social care is another indispensable part of the care provision. In comparison to healthcare which is commissioned and largely delivered by the NHS, social care is mainly commissioned by local authorities and individuals and provided by many different sources, which is a key issue in healthcare fragmentation. Some older people do not realise that the social care provision is not part of the NHS (Mortimer and Green, 2015). With regard to the content of care, a healthcare care need is more related to the treatment, control or prevention of a condition, while a social care need is more about supporting people with their daily activities (Department of Health, 2012b).

In fact, there is no simple definition of social care. However, it is agreed it covers a wide range of services to people either in their own homes or in a care home (BBC News, 2008). It also covers day centres, which help people with daily life. Services like helping with washing, dressing, feeding or assistance in going to a toilet are also included, as well as meals-on-wheels and home-help for people with disabilities.

Similar to the NHS, social care is also under substantial pressure due to the growth in the ageing population. However, despite the high demand, real public spending on social care organised by English local authorities fell by 1.0% between 2009–10 and 2015–16. Specifically, in 2005/06 local authorities spent a total of £8.26 billion in real terms on older people's care services, but the latest local authority revenue accounts reveal that the budget for older people's

social care fell to only £6.31 billion in 2015/16 (Health and Social Care Information Centre, 2014). This represents a decrease in real terms of £1.95 billion in just 10 years while the population aged 65 and above grew by 15.6% during this period.

- Long-term conditions

In addition, the prevalence of long-term conditions aggravates the burden of the health system. In England, there are around 15 million people who have a long-term condition and the number of people with multiple long-term conditions is set to rise to 2.9 million in 2018 from 1.9 million in 2008. Age is a major factor in the prevalence of long-term conditions, and 58% of those aged 60 and over report having a long-term condition, with 25% of over 60s possessing two or more (Department of Health, 2012a). Consequently, the nature of ill-health has shifted from acute illness to chronic conditions and long-term frailty (Government Office for Science, 2016).

People with long term conditions account for 50% of all GP appointments, 64% of outpatient appointments, and 70% of all inpatient bed days. In total, around 70% of the total health and care spent in England (£7 out of every £10) is attributed to caring for people with long-term conditions, which means that 30% of the population accounts for 70% of the healthcare services' spending. In particular, people with limiting long-term conditions continue to be the most intensive users of the most expensive services (Department of Health, 2012a).

In summary, older people with long-term conditions are likely to be the largest users of both the NHS and social care, but the service is fragmented and may be unable to meet their needs. A healthcare service which possibly can help people self-manage their long-term conditions and avoid hospital admission is the key to a more sustainable healthcare system in future.

2.3.1.2 The definition of Community-based care

Community-based care refers to those care services offered in, or closer to, people's homes, within and across 'primary care'(NHS) and social care settings. Community-based care enables people to keep their normal routine, staying close to family and friends (The NHS Constitution, 2013). It is the increasingly preferred means of providing care for the majority of longer term and mild-to-moderate conditions. The scale of these community services remains poorly understood and less than well served judging by the way the debate on health services often defaults to 'GPs and hospitals' or 'primary and secondary care'.

Recently, the Kings' Fund published a report, i.e., *Reimagining community services: making the most of our assets*, which defines services in the community both narrowly and broadly.

The narrow definition includes those services provided by organisations who are responsible for this area such as community NHS trusts and local authorities; the broader definition encompasses the related services delivered in a community setting such as general practice, social care and mental health as well as the contribution of the private sector, third sector organisations, carers and families. Figure 2.10 presents where the community healthcare services fit that support health and care (Charles *et al*., 2018).

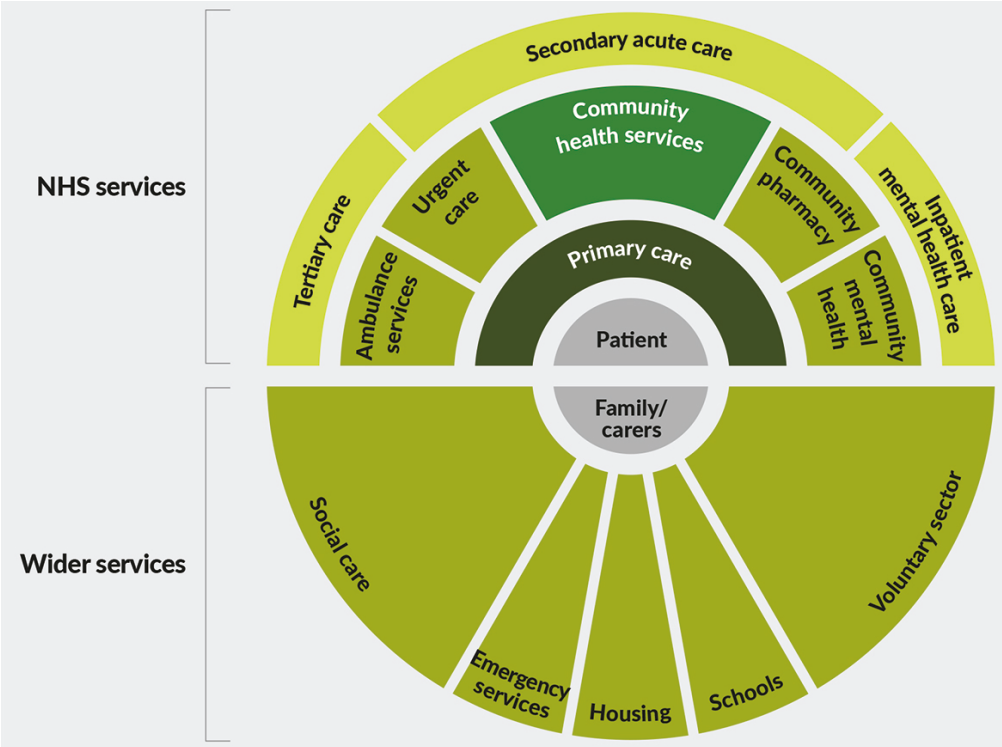


Figure 2.10 The community health services fit within systems that support health and care (Charles *et al*., 2018)

In fact, patients receiving care in the community setting often have multiple and complex health needs and rely on different health and social care services working together to meet their needs. In this sense, community-based care not only includes narrowly defined community services, but also contains a wider range of sectors and services that deliver care and support in the community setting.

2.3.1.3 The Practicability of Community-based Care

"A shift from hospital-based healthcare to community-based healthcare is a way to empower patients by giving them more control and treating them in the location that suits them best" (Greenway, 2017). Specifically, community-based care has an advantage in terms of its geographical reach. Compared to hospital care, care within the community is closer to home, which is more convenient for patients, especially older people. Patients are also familiar with their own communities and thus they are more likely to prefer services in their communities to

relatively far and unfamiliar hospitals. It is said that the vast majority of older people are spirited and resilient, and they want to live life on their own terms, preferably in their own homes, for as long as they possibly can (Mortimer and Green, 2015).

Community-based care can possibly avoid hospital admission and reduce the demand of secondary care (Charles *et al*., 2018). It is estimated that about 100 million patients contacts community healthcare services per year (Gershlick and Firth, 2017) and average 340 million consultations in GP surgeries (Curry, 2015). According to the Government Office for Science report, i.e., *Future of an Ageing population,* the management of chronic disease has gradually moved from secondary care to primary and community care over the last two decades (Government Office for Science, 2016). This is particularly meaningful for older people with long-term conditions as they would be able to take advantage of community care recourses to self-manage their conditions.

2.3.1.4 The Vision of Community-based Care

In reality, the increase in community-based care remains slow. It is hoped that a higher proportion of care could be delivered at home or closer to home and the fragmentation of service delivery could be reduced. The King's Fund (Charles *et al*., 2018) proposes ten design principles to guide future models of community-based care:

- Organise and co-ordinate care around people's needs
- Understand and respond to people's physical health, mental health and social needs
- Make the best use of all the community's assets to deliver care to meet local needs
- Enable professionals to work together across boundaries
- Build in access to specialist advice and support
- Focus on improving the population's health and wellbeing
- Empower people to take control of their own health and care
- Design delivery models to support and strengthen relational aspects of care
- Involve families, carers and communities in planning and delivering care
- Make community-based care the central focus of the system.

Across the ten principles, the need for care to meet people's requirements has been emphasised in the first three principles. To achieve this goal, first and foremost, the care should be available and accessible by the users. Details on the access of healthcare services is discussed in the next Section 2.3.2.

In summary, community-based care services refer to care services that are provided at or closer to people's homes, i.e., 'community as the hub' of the care, which makes it possible for people to control and manage chronic conditions in their community. Community-based care services are the key to the future of the NHS (Scott, 2013). In order to promote community-based care services, it is necessary to understand two related concepts, accessibility and care pathways, which are discussed in the following two sections.

2.3.2 Accessibility of healthcare services

Access is a prerequisite for patients to use available healthcare services and improve the quality of healthcare systems. Recently, the European Patient Forum prioritised the promotion of *patient's access to healthcare equally* (European Patient Forum, 2016). In order to promote the accessibility of community-based care, it is important to understand what access and accessibility are and why we connect accessibility with Inclusive Design.

2.3.2.1 Definition

Etymologically, access refers to a way of entering or reaching a place, the opportunity or right to use or visit; and accessibility is defined as how easy something is to reach, enter, use, see and understand (Oxford English Dictionary, 2018). Hence, literally, accessibility relates to the possibility of access. Access is essentially about whether you can use something or not, while accessibility is about designing a good experience, i.e., ease of use, or what works well for everyone (Pellicore, 2016). In terms of healthcare, access is actually a multi-dimensional concept and there is no universally accepted definition.

Access can be seen from the system's perspective, which is categorised into five specific dimensions relating to the characteristics of the healthcare system and expectations of patients (Anderson, 1968; Penchansky and Thomas, 1981). The five dimensions are: affordability, availability, accessibility, accommodation, and acceptability. Some researchers emphasise access to health care from a patient's perspective, i.e., patient-centred access to health care (Levesque, Harris and Russell, 2013). Access is viewed as the opportunity to identify healthcare needs, to seek, reach, obtain or use health care services, and to actually have a need for services to be fulfilled. How to examine, measure and promote the equity for patients in terms of access to health care has been widely discussed (Frenk, 1992; Waters, 2000; Goddard and Smith, 2001; Oliver and Mossialos, 2004).

The 5As definition of access was readapted by the Patient Access Partnership[1], to availability, adequacy, accessibility, affordability and appropriateness (Patient Access partnership) in order to better reflect the patients' perspective. The 5As principles stand for the following:

Table 2.4 5As principles of access

Availability	Whether services are available in the first place
Adequacy	Whether there is an adequate and continued supply of available services
Accessibility	Whether the services are effectively available for utilisation
Affordability	A system for financing health services so people do not suffer financial hardship when using them.
Appropriateness	Available health care resources should meet the needs of different population groups

The 5As principles put the availability of the service first and then consider whether the availability of the service is adequate. The term accessibility according to the 5As principles is measured according to the utilisation of the service, which depends on the physical accessibility and acceptability, as well as timelessness of services, not merely whether the services are supplied adequately or not. Affordability and appropriateness are more about how a service is designed to meet the patients' financial capacity and different population groups' needs respectively.

It is equally important to consider access from both patients' and the healthcare system's perspectives. Only if we understand patients' healthcare needs can we possibly establish a better health care system; and only if the health care system is well-built can it possibly accommodate patients' needs.

In this research, access denotes the interaction between healthcare services' demand (system's attributes) and patients' capabilities (patients' attributes) within a given context, which is influenced by the characteristics of those who supply and those who use the services. If the healthcare service's demand on a patient's capability is within his or her capability, the patient is more likely to access the healthcare service. By contrast, if the healthcare service places too much demand on a patient's capability, the patient may be excluded from this service. Therefore, identifying the level of patients' capability and related capability needs is necessary

[1] Patient Access Partnership is a non-profit organisation to ensure equitable patients' access to quality healthcare in the European.

to improve the accessibility of the healthcare system, which coincides with the scope of Inclusive Design.

In addition, it is necessary to compare access to healthcare services through Inclusive Design with access through patient engagement, patient involvement, shared decision-making, and collaborative care. These latter concepts focus on involving patients in their care management, which could affect their access to healthcare services (Valentin-Hjorth *et al.*, 2018). Inclusive Design focuses on patients' capabilities to meet healthcare services' demands which is a prerequisite for them to then engage, involve, make shared decisions and collaborate with providers. The next section describes how Inclusive Design can be used to improve the accessibility of healthcare services.

2.3.2.2 Inclusive Design and accessibility of healthcare

Utilising an Inclusive Design approach in designing healthcare services could possibly improve the accessibility of healthcare. This is because, like products, services also make demands on their users, in the context of a particular task being undertaken in a particular environment (Figure 2.11).

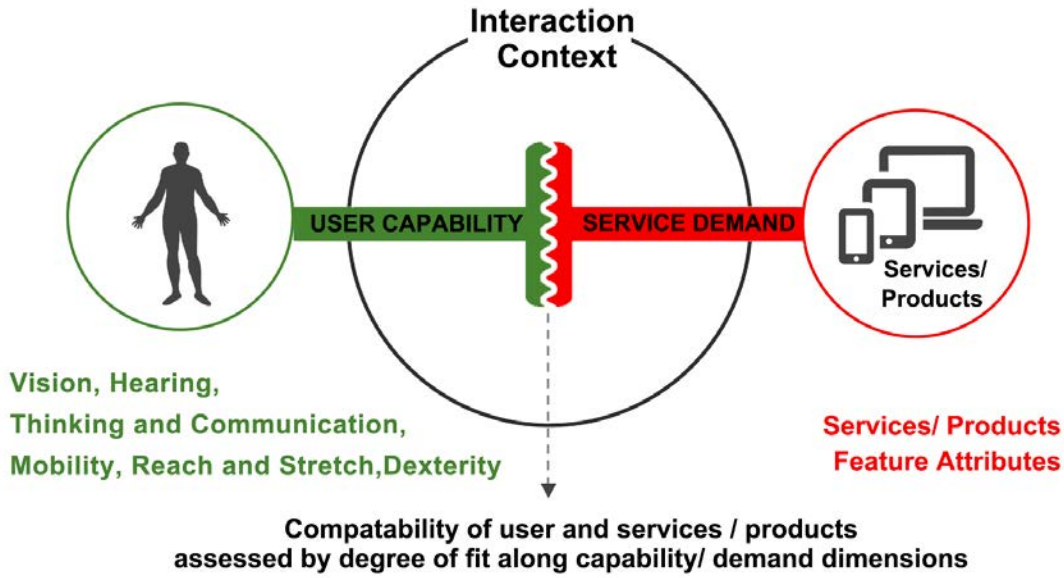


Figure 2.11 Interaction context-demand and capabilities (Persad *et al*. 2007). Reproduced from www.inclusivedesigntoolkit.com with permission.

When such demands exceed the capabilities of a particular user, exclusion or difficulty may arise. Products and services which are designed with these challenges in mind are more likely place moderate demand on the user, increasing accessibility and ultimately the utility of the service (Schifferstein and Hekkert, 2008). Therefore, if we consider the needs of people with

reduced functional capability during the service design process, those people are more likely to access healthcare.

Specifically, any interaction with a product or service typically requires a cycle where the user's capabilities are used to perceive, think and then act (see Figure 2.12). Perceiving normally involves sensory capability like *vision* and *hearing*. Thinking is also required to process the information received through the senses. Motor capabilities like Reach & Dexterity may also be needed, e.g., to hold the phone and press the right buttons. A person with vision or hearing impairments may be less likely to perceive what is required and the interaction cycle cannot be completed without external aid. Therefore, multiple capabilities are required in using a product or service and it is important to consider capabilities together to create effective Inclusive Design products or services (Clarkson *et al.*, 2007).

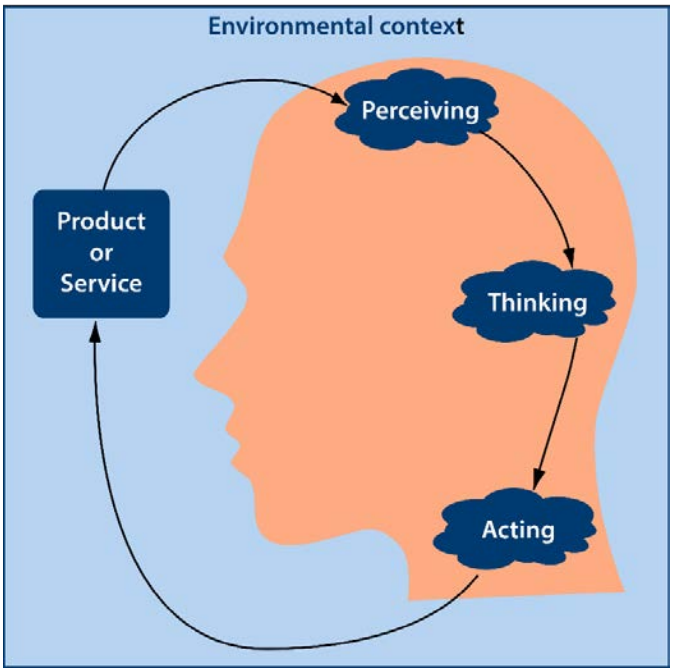


Figure 2.12 An interaction with a product/ service (Clarkson *et al*., 2007)

Take Mrs. Smith, who is 70 years old and has COPD, making an appointment with her GP as an example to illustrate this process. She lives on her own and her family lives quite far away. In order to book a GP appointment, she needs to know how to make an appointment and who is her GP. When she calls the reception of the GP, the receptionist may offer her two time slots and she needs to choose the one most suitable for her. After the call, she may need to record the appointment in her diary to remember it. During this whole process, her hearing capability may affect the success of the conversation between her and the receptionist. Similarly, her thinking ability may affect whether she can answer the receptionist's questions clearly. Other

factors like whether many people call the surgery at the same time as she does and whether the environment is quiet could also affect the whole task. If there were some tasks during the booking process beyond Mrs. Smith's capabilities, she would not be able to make an appointment successfully and then her COPD would become worse.

By considering patients' demands in different care contexts, care providers are able to offer better services within their capabilities and thus increase accessibility to this healthcare service. Successful Inclusive Design requires a balance between the demands a product or service places on its users and the users' capabilities, along with a number of design metrics and data to enable evaluation. It is more useful to interpret user capability profiles, not as a source of what users cannot do, but as a means of inferring what they can do (Clarkson and Keates, 2003). Therefore, besides knowing the number of people who are potentially excluded from a system, the most important point is how these data can be used to improve the healthcare service.

The next section describes the Inclusive Design methods for assessing the demands on patients and corresponding exclusion calculations of healthcare services are introduced.

2.3.2.3 Assessing demand and exclusion of healthcare service

The healthcare services' demand on patients can be assessed by the pre-defined scales, which have been constructed based on the questions in the 1996/97 Disability Follow-up to the Family Resources Survey (DFS) (Grundy *et al*., 1999). The survey asked participants questions about whether they could perform certain tasks, e.g., 'Can you understand loud speech in a quiet room?'. The tasks were then arranged into ordered scales (see an example of hearing in Figure 2.13). Higher demand on peoples' capabilities causes higher scale ratings, and the symbol ">" off scale means it is excessive for a mainstream service.

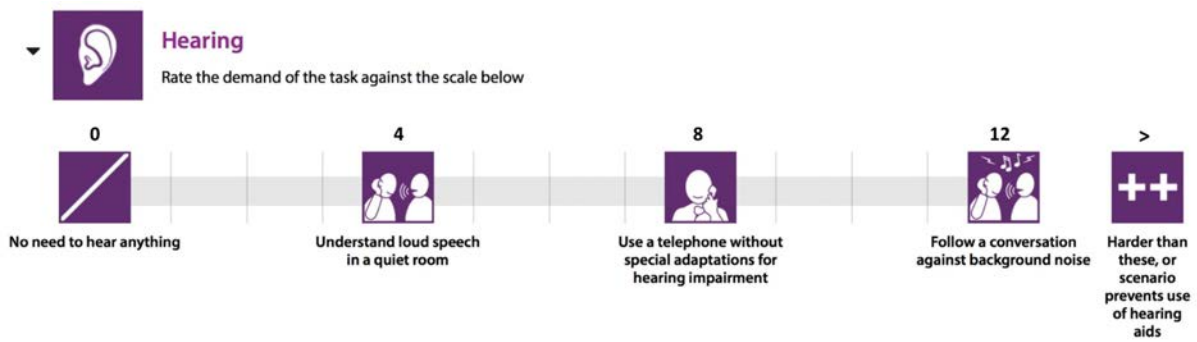


Figure 2.13 A scale for assessing hearing demand based on data from the Disability Follow-up Survey

Some of the capability categories have several scales. For example, the category '*mobility*' has scales measuring *walking, stair climbing*, and *standing and balancing* (Figure 2.14).

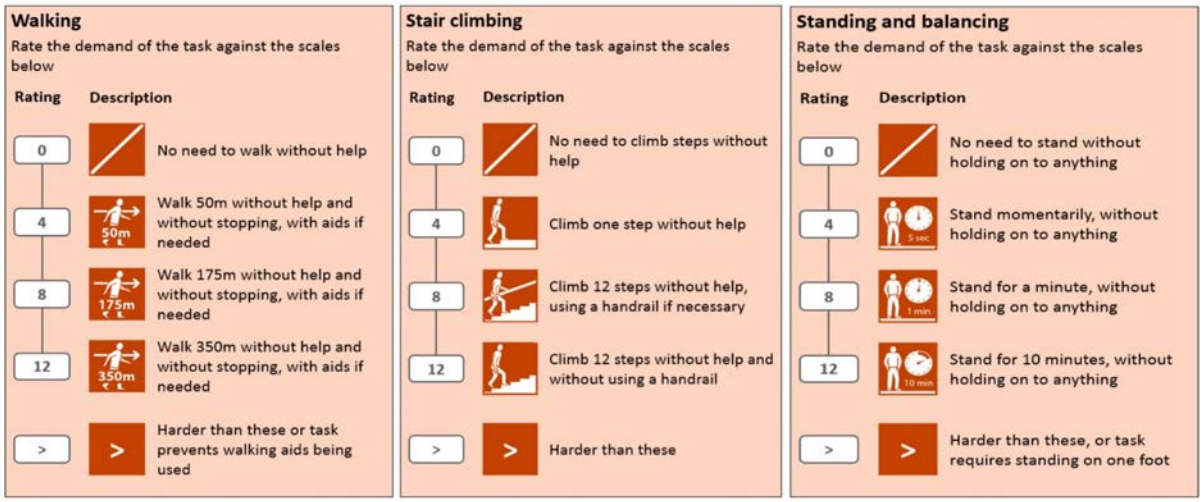


Figure 2.14 Scales for assessing mobility demand based on data from the Disability Follow-up Survey

To assess a product or service, the assessor estimates the level of the capability needed in order to use the product or service and then compares this level of capability to each of the tasks in the survey. For example, the task 'make a telephone call' places demands on patients' vision and hearing capabilities (to hear clearly throughout the call requires hearing ability, and to see the number buttons needs vision ability), reach and dexterity (to hold the phone requires strength, while to reach forward and up, and press the number buttons needs dexterity), and thinking capability (to remember the telephone number to call requires memory, and to communicate with the receptionist needs speech comprehension and speaking ability). The demand of this task on patients' hearing capability is close to the scale 8, i.e., use telephone without special adaptations for hearing impairment, so the hearing demand is rated scale 8 (Figure 2.15). The level of the tasks' description is matched against the details of the pre-defined scales (Waller, Langdon, and Clarkson, 2009).

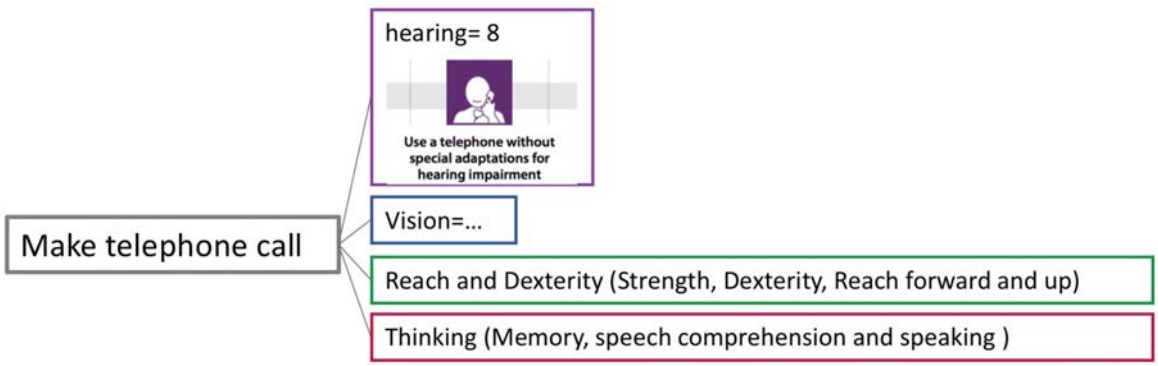


Figure 2.15 Assessing the demand of the task 'to make a telephone call'

The number of people who could be excluded as a result of these demands can also be calculated from the survey data using the Exclusion Calculator. Specifically, the "Exclusion

Calculator" (an Inclusive Design tool) produced by the University of Cambridge Engineering Design Centre uses a large database of British users (from DFS) with a range of disabilities to estimate the proportion of the British population that is unable to use a product or service because of the demands that it places on the users' capability. A version of the *Exclusion Calculator* is freely available on the Inclusive Design Toolkit website (Clarkson *et al*., 2007).

By inputting the estimated demands of each task along the care journey, the "*Exclusion Calculator*" can estimate the number of people within the general population excluded from accessing healthcare services (in every task and on the whole care journey). Figure 2.16 shows an example of measuring hearing exclusion for the task 'make a telephone call'. In total, about 2% of the whole population could be excluded due to the task's demand on their hearing capability. It is important to note that this calculation is based on whole population data and not on one particular disease, but it still could possibly give useful insights regarding potentially the most challenging tasks for the population and provide evidence to prioritise the parts of the services that need to be improved. In fact, there were nearly 1000 participants who self-reported that they have a respiratory issue and could benefit from community-based pulmonary rehabilitation (PR), and this provides a possible estimate of the exclusion number for COPD patients accessing the care services. A more detailed discussion is presented in Chapter 5.

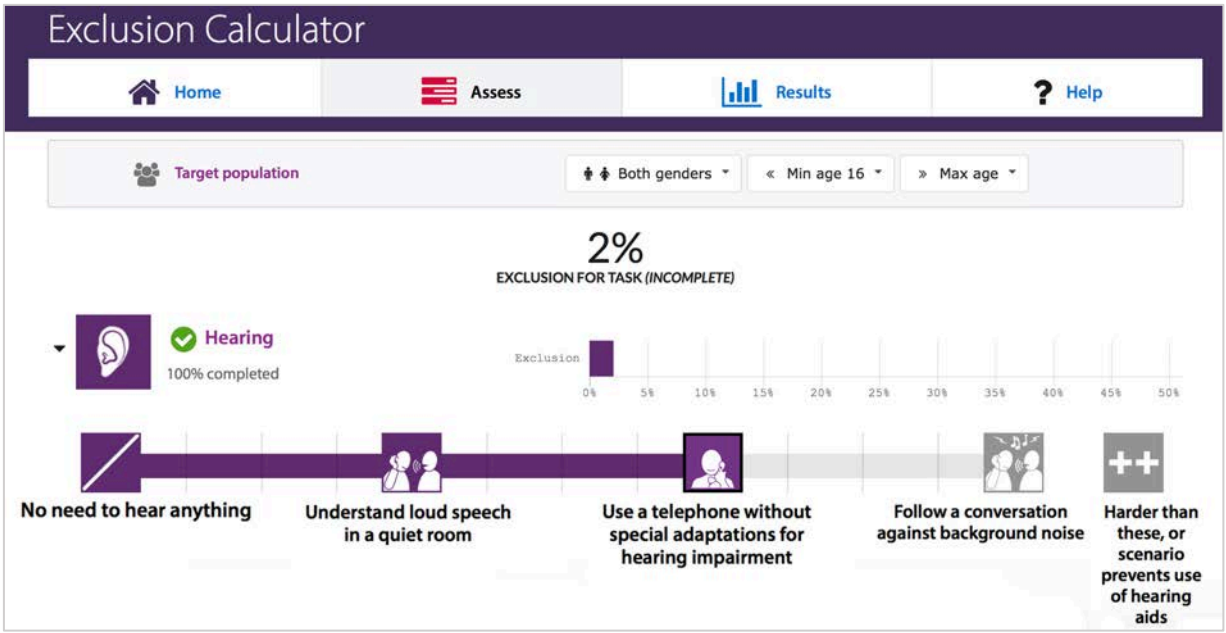


Figure 2.16 Calculating exclusion (i.e., the hearing exclusion for the task 'make a telephone call')

In reality, the healthcare services' demand on patients' capability varies in different care contexts. Therefore, in order to improve people's access to healthcare services, it is necessary to understand the care process, i.e., care pathway, which is reviewed in Section 2.3.3.

2.3.3 The care pathway

2.3.3.1 Definition

'Care pathway' or 'care journey' are both terms used to describe the process of healthcare service delivery. Pathway refers to a track that constitutes or serves as a path, and it is more like a standard path for people to follow; while journey refers to the act of travelling from one place to another, and it pays more attention to individuals' actions (Oxford English Dictionary, 2018). Specifically, care pathways (also known as clinical pathways or care maps) are more generic and described from an organisational perspective (Vanhaecht, De Witte and Sermeus, 2007; Schrijvers, van Hoorn and Huiskes, 2012). A pathway may take the form of an integrated management plan that provides a sequence and timing of actions necessary to achieve a standard care process and optimal efficiency for clinicians (Panella, Marchisi and Di Stanisla, 2003). They are the clinical management tools used to help care workers to understand their working flow. For example, the main stages in the NHS primary care pathway of COPD rehabilitation are shown in Figure 2.17.

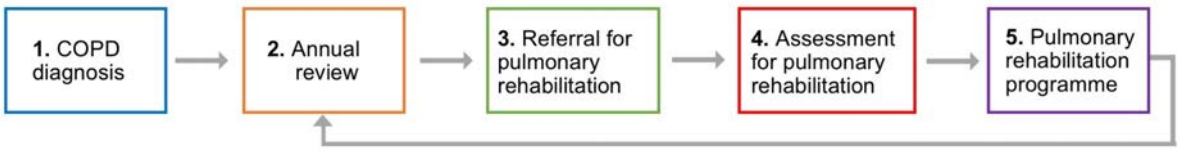


Figure 2.17 The main stages in the NHS primary care pathway of COPD rehabilitation

While care journeys describe the process of healthcare service from the patients' perspective. Patient's care journey refers to the process that he or she is likely to go through in order to receive care.

2.3.3.2 The role/impact of care pathway

The UK National Institute for Health and Care Excellence (NICE) has introduced NICE Pathways which is an interactive tool for health and social care professionals providing fast access to NICE guidance and associated products.

Schrijvers, van Hoorn and Huiskes (2012)summarises the theoretical advantages and disadvantages of care pathways for patients and professionals. The benefits of applying care pathways are: i) shortening the production process with faster diagnosis, ii) increasing

coherence between different professionals, iii) reducing the risk of errors, reducing costs, and v) increasing job satisfaction. The disadvantages of using care pathways are: i) dehumanisation of work, ii) an increase in costs, iii) lower job satisfaction, and vi) a decline in the diversity of professional work. Despite the fact that some care pathways' strengths and weaknesses are paradoxical, care pathways can provide guidance and quality that are standardised and available for healthcare professionals to consult in order to specify their work at every step.

In this research, we mainly use care pathways to understand how community-based healthcare services are provided to users and to identify these services' demands on users' capabilities along their care journeys. To achieve this, care pathways are divided into a series of specific tasks to be further analysed.

2.3.3.3 Task analysis for care pathway

Task analysis is a process of obtaining detailed information from users about what they are required to do, in terms of actions and/ or cognitive processes, to achieve a task or goal (Annett and Duncan, 1967). There are various forms of task analysis and in this research, we use hierarchical task analysis, in which tasks are decomposed into sub-tasks until a sufficient level of detail (a suitable stopping place) is reached (Ainsworth and Marshall, 1998; Shepherd, 2001; Annett, 2003). The suitable stopping place here is matched with the pre-refined scale of the Exclusion Calculator, which is used to calculate the level of exclusion (the detailed see Section 2.4.3.3). The information provided by the task analysis is useful to investigate how people perform tasks, to identify the ability or knowledge needed by users to perform the task or to use the service, and thus to understand what difficulties users may face and suggest possible design improvements (Coleman *et al.*, 2007; Seidel, 2010).

In terms of care pathways, task analysis can be used to subgroup the activities that healthcare professionals need to accomplish along the care pathway and provide clues about patients' activities along their care journey. For example, for the General Practitioner (GP), the COPD diagnosis within the GP surgery can be further broken down into three tasks: i) make an appointment with the patient; ii) check and consult; iii) give a diagnosis or refer the patient for a further check. Correspondingly, patients' care journey for diagnosis can be divided into the following steps: i) make an appointment with the GP; ii) go to the GP practice; iii) have a GP consultation; vi) obtain a diagnosis (see Figure 2.18).

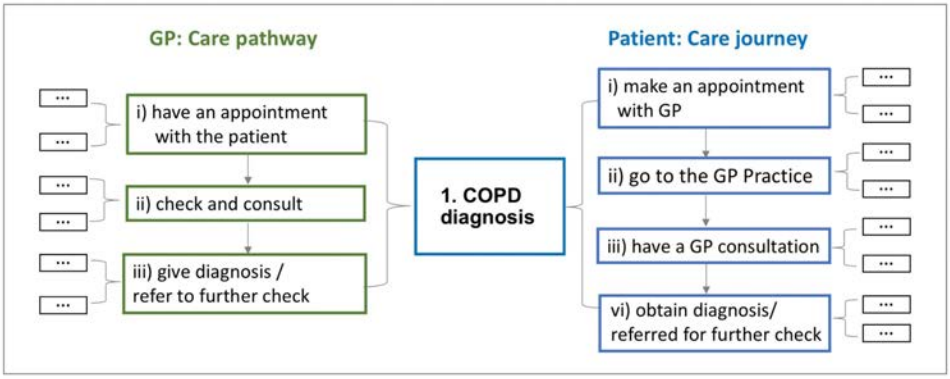


Figure 2.18 Care pathways / journeys consist of specific tasks

It is worth noting the difference between the tasks of GPs and patients. For GPs, whether they give patients a proper 'check and consult' is likely to be most important, while for patients, whether they can 'make an appointment with the GP' and 'go to the GP practice' may have a greater impact on them. If the patients do not obtain an appointment, they are unable to see the GP and if the transport to the GP practice is challenging for the patients especially those with disabilities or without convenient transport facilities, they may not be able to reach the GP surgery. This means the patients may have differ journeys from the healthcare professionals and there might be some unobvious (less visible) difficulties that prevent them from accessing healthcare services. Therefore, it is necessary to understand the differences between the healthcare professionals' care pathways and the patients' care journeys and thus identify patients' needs along their care journeys.

Section 2.3.2 and 2.3.3 explore the literature on Inclusive Design approach to improve healthcare services, the next section investigates other approaches to enhance healthcare services.

2.3.4 The application of other approaches to healthcare services

There are a range of approaches that have been applied to improve healthcare services and it is important to analyse them in order to better position the Inclusive Design approach for healthcare service design. Table 2.5 summarises the aims and strengths of existing approaches (including models and methods) that have been used to improve healthcare services. Some models place emphasis on supporting changes in the NHS, such as the *change model* and *change management*; some from systems' perspectives provide guides or add value to improving healthcare such as *systems engineering* and the *systems approach*; some design approaches, e.g., *the Experience Based Design approach* (*the ebd approach*), focus on designing better experiences for patients, carers and staff, which also involves looking at care

journeys as well as the emotional journeys people experience when they access services. So far, no practical approach has focused on improving healthcare services from the perspective of understanding patients' capability-related needs.

Table 2.5 A comparison between the focus of existing approaches for healthcare services

Models	Aims of the models	Strengths
Model for improvement	A tool for accelerating improvement, based on three fundamental questions and the Plan-Do-Study-Act cycle to test changes in real work settings (Langley *et al.*, 2009)	· Ensures that teams identify a common purpose · Establishes an appropriate set of measures for improvement · Identifies those changes that are likely to lead to improvement
Change model	A framework for change to help NHS commissioners and providers improve how they go about improvement and deliver NHS goals for quality and value (NHS England, 2018)	· Creates shared ways of thinking about change · Brings together services users, workforce and change partners · Links up activities across the whole system
Change management	A model for supporting change with clinicians, managers and senior leaders to implement health and care solutions in workflows and practice (Canada Health Info way)	· Reflects leading change practices and lessons learned · Facilitates stakeholder-led improvements to practice · Focuses on successful, evidence-based implementation
Waterfall model	A holistic approach that focuses on the need for effective design controls during the design and delivery processes (Centre for Devices and Radiological Health, 1997)	· Validation demonstrates that the solution meets the user needs · Verification shows that the output meets the input requirements · Review systematically examines the emerging solution
Lean principles	A process to facilitate improvement in patient care with existing resources, often meaning the same things can be achieved using fewer people (Bryant, 2017)	· Improves quality and safety with fewer accidents and errors · Improves delivery as better work gets done sooner · Improves throughput as the same people are capable of much more
Driver diagram	A 'theory of change' within the system, that can be used to plan improvement project activities, collaboratively by the project team(NHS Improvement, 2018)	· Captures a clearly defined and measurable aim · Identifies the drivers which will contribute to the aim · Formulates the ideas for change designed to meet the aim
Systems engineering	An interdisciplinary approach to the realisation of successful systems, focused on delivering the required functionality to meet customer needs (INCOSE UK, 2009)	· Provides a holistic view of systems to enable improvement · Focuses on customer needs through to system validation · Uses models to make sense of complex problems
Systems approach	A set of questions encouraging the integration of *people, systems, design, risk and programme management* perspectives (Royal Academy of Engineering,2017)	· Adds value to existing health and care improvement initiatives · Questions change thinking and actions change outcomes · Focuses on delivering system-wide improvement
Experience based design (ebd) approach	An approach of designing better experiences for patients, carers and staff, capturing the experiences of those involved in healthcare services (NHS Institute for Innovation and Improvement, 2009)	· Presents the insights gained in the form of a short-edited film · Encourages collaboration between patients and staff · Improves the experience of the service or care pathway
Design models	An iterative approach to *explore*, *create* and *evaluate*, leading to a clearer understanding of user needs and better solutions that meet these needs (Waller *et al.*, 2015)	· Identifies stakeholder needs for system change · Generates a range of possible solutions for change · Validates the solutions against stakeholder needs
Double diamond	An approach that encourages *divergent* and *convergent* thinking in problem solving and in the process of problem identification (Design Council, 2005).	· Accentuates the need for rigorous problem identification · Encourages creative thinking prior to the selection of design solutions · Focuses on iterative development before delivery of a solution
Human factors	A description of the scientific discipline concerned with the understanding of interactions among humans and other system elements (International Ergonomics Association, 2018)	· Studies the relationship between human behaviour and safety · Changes organisation and culture to enhance performance · Helps health and care staff to act as a barrier against harm
Safety management	A set of approaches to minimise the number of accidents and incidents and to maximise the number of intended and acceptable outcomes (Hollnagel *et al.*, 2015)	· Focuses on reducing risks as well as increasing opportunities · Reduces the number of accidents and incidents Increases the chance of success under all conditions

In addition, it is imperative to draw on the research that has investigated design approaches (e.g., the *ebd approach* and *Double diamond* in Table 2.5) in relation to healthcare services. The *ebd approach* was designed for and within the NHS to develop solutions that offer patients a better experience of treatment and care. In particular, the recognition of the importance of emotion is a core principle that distinguishes the *ebd approach* from other approaches. It has

already been used in a range of clinical services, including cancer, diabetes, drug and alcohol treatment, emergency services, genetics, inpatient units, intensive care, mental health, orthopaedics, palliative care and surgical units (The point of care Foundation, 2016). The *ebd approach* captures the aesthetics of experience, focusing on the whole interaction with the service experienced. It might also be able to capture patients' capability-related experiences, but it is not focused on the diversity of capabilities among patients.

The *double diamond* has also been used in projects that apply design thinking to innovate healthcare services. For example, it was used to guide work that aims to help people living well with diabetes (Sangiorgi and Freire, 2010). The purpose of using the *double diamond* is encouraging divergent and convergent thinking in problem identification and solving. It may help identify capability-related challenges of patients and propose a solution to address the challenges, but it is not specific to explore patients' diversity of capabilities either.

In addition, *service design* as a design approach has been applied to improving healthcare services in recent years (Sangiorgi and Freire, 2010; Silvis, 2015; Chamberlain *et al.*, 2015; Fry, 2017). It emphasises co-design by including service providers, end-users and stakeholders in the design process. The outcome of applying *service design* to specific healthcare services is usually a new service model that considers the benefits of both care providers and patients. In fact, the *ebd approach* is a part of *service design*.

While the principle of Inclusive Design is to design for the demand of capability in a particular context. Therefore, it is recognition of the diversity of capability which makes Inclusive Design different from the service design approach which is fundamentally based on average descriptions of individuals.

To summarise Section 2.3, community-based care, which aims at providing care at or closer to home and avoid hospital admission, is a promising and encouraging choice to meet the healthcare demand for long-term conditions among an ageing population. Identifying the tasks of community-based care pathways makes it possible to estimate the service's accessibility, capture patients' needs and thus improve patients' access to care. The related patients' attributes are discussed in Section 2.4.

2.4 Patients (sub-question 3)

This section explores patients' characteristics and gathers insights into evidence to answer the sub-question 3: *To what extent do people's capabilities affect their access to community-based*

healthcare services? Three main topics are discussed: people's capabilities, healthcare experience, and the self-management of long-term conditions in the community (Figure 2.19).

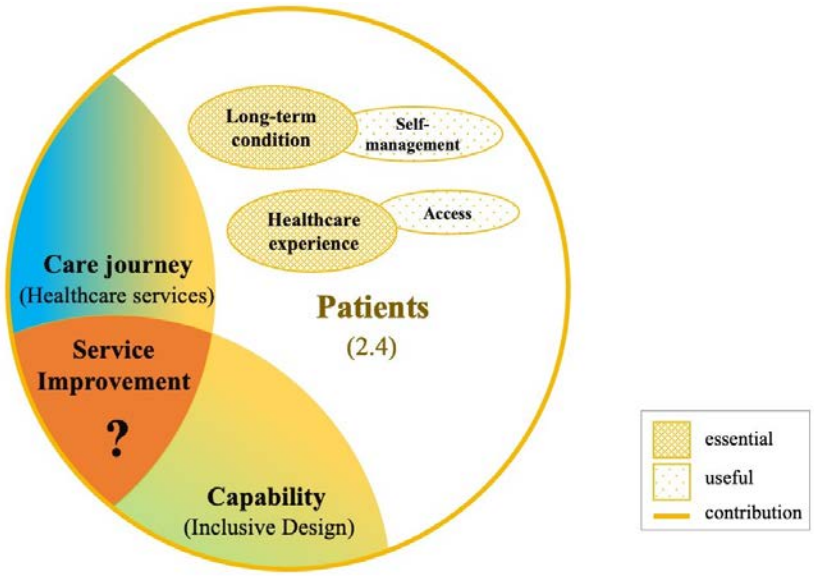


Figure 2.19 Outline of literature review about the patients

2.4.1 Capability

Using any services or products makes demands on users' capabilities. For example, making a GP appointment by telephone requires motor ability to hold the phone, sensory ability to hear, and cognitive ability to interpret. Similarly, travelling to the GP surgery may put particular strain on the patient. Understanding the different types of user capabilities and the impact they have on service use is essential to designing healthcare services inclusively.

2.4.1.1 Definition and categories

Capabilities are a set of various functions that a person can achieve - what people are actually able to be and to do (Sen, 1992; Terzi, 2005). In short, capability refers to the ability to do something (Oxford English Dictionary, 2018). In the context of this research, capability refers to people's ability to access health care.

Capabilities may be considered to consist of sensory capabilities (vision and hearing), cognitive capabilities (thinking and communication) and motor capabilities (locomotion, reach & stretch and dexterity) (Clarkson *et al.*, 2007; Schifferstein and Hekkert, 2008; Waller *et al.*, 2010). In 2013, the same authors (Waller *et al.*, 2013) proposed a simpler clustering of user capabilities, i.e., vision, hearing, thinking, dexterity and reach, and mobility, which is more suitable for product interaction. The detailed definition of the five main categories is below:

- **Vision** is the ability to use the colour and brightness of light to detect objects, discriminate between different surfaces and discern the details on a surface.
- **Hearing** is the ability to discriminate between specific tones or speech from ambient noise and to tell where sounds originate.
- **Thinking**, also known as 'cognition', refers to the ability to process information, hold attention, store and retrieve memories and select appropriate responses and actions. The ability to understand other people and express oneself to others can also be categorised under thinking (Figure 2.20). It includes concentration, memory, literacy, speech comprehension and speaking abilities.

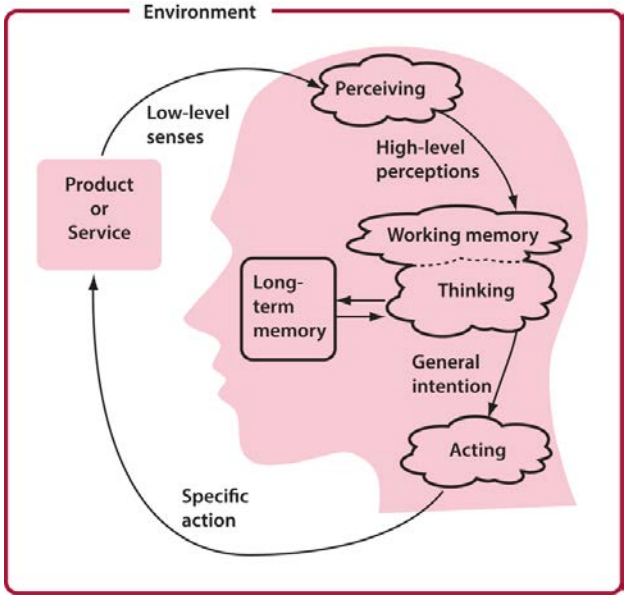


Figure 2.20 The schematic of how the different processes involved with thinking relate to each other and to a product in the world (Clarkson *et al*., 2007)

- **Reach and Dexterity** concerns the abilities of the arms. It constitutes the ability to reach different places around the body, perform fine finger manipulation, pick up and carry objects and grasp and squeeze objects. It includes the ability to reach forward and up, dexterity, and lifting strength.
- **Mobility** is the ability to move around, climb steps and balance.

Although a healthcare service can be regarded as an 'intangible product', the interaction between a healthcare system and a user is similar to the interaction between a 'tangible product' and a user, so the more relevant product interaction categories of capabilities are used in this research.

2.4.1.2 Factors that cause capability change

Ageing is one of the main factors that causes a person's capability to change. Understanding age-related capability change, especially the patterns of capability loss for older people, is useful to predict their capability-related needs when they access healthcare services. Research aiming to understand patterns of capability loss among elder users of product and services has analysed the data from a population-based study which recruited a representative sample of 13,004 people aged 65 years and over from 5 sites in the UK (Seidel *et al.*, 2009). The research has found there are patterns of capability loss among older people. Locomotion (mobility) was the first ability to be lost, followed by reaching, thinking, hearing, vision and dexterity. Women were consistently younger at capability loss than men except in terms of hearing.

Specifically, Figure 2.21 shows age at the point of capability loss. Half of the sample lost their locomotion (mobility) by 78 years, of age reaching ability by 81 and thinking ability by 82, while hearing, vision and dexterity were lost relatively later.

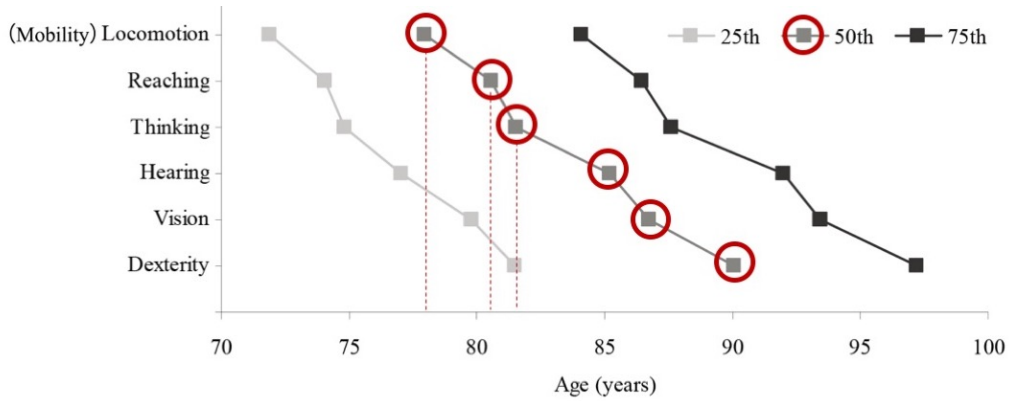


Figure 2.21 Age at capability loss by percentiles, 1990/94-2003 (Seidel *et al.*, 2009)

The research also found gender differences for median age capability loss. As we can see in Table 2.6, except vision, there are significant differences between men and women in all abilities, especially the median age for reach loss (men:84 years vs women: 78 years).

Table 2.6 Median age at capability loss by gender, 1990/94-2003(Seidel *et al.*, 2009)

Ability	Age (95% CI)		P-value*
	Men	Women	
Vision	87.1 (86.2-88.3)	86.5 (85.7-87.2)	0.108
Hearing	82.9 (81.8-83.8)	86.7 (86.1-87.3)	<0.001
Thinking	82.5 (81.8-83.3)	81.1 (80.5-81.5)	<0.001
Locomotion (Mobility)	78.6 (77.8-79.2)	77.6 (76.9-78.1)	0.005
Reaching	84.1 (83.4-85.0)	78.3 (77.7-78.9)	<0.001
Dexterity	91.4 (90.3-92.3)	89.3 (88.4-90.1)	0.003

CI, confidence interval
*P-values were obtained from the log-rank test; a value <0.05 indicates a statistically significant difference between men and women

Conditions, especially long-term conditions, are another main factor that cause people's capability loss. Older people with long-term conditions are likely to be the most vulnerable people with reduced capabilities as most of them cope with at least one condition, and many deals with two or more conditions (Department of Health, 2012a). Research by Ettinger *et al*. (1994) on conditions and symptoms that cause difficulties in performing 17 physical tasks in older people's daily lives has conducted research among 5201 community-dwelling people over 65 years old. They found that arthritis and other musculoskeletal diseases were given as the primary causes of difficulty in performing physical tasks by 49.0% since the participants reported difficulty in any task, followed by heart disease (13.7%), injury (12.0%), old age (11.7%), lung disease (6.0%), and stroke (2.9%). This means some diseases possibly have a direct impact on people's capabilities.

2.4.1.3 The impacts of capability change on accessing healthcare service

People may have difficulties in accessing healthcare services due to their capability changes over time. For example, older people who have eye problems may have some difficulties such as reading the bus stop and medical instructions. Therefore, they may be unable to take a bus to see a GP or visit hospital, or they may not take medication correctly. Similarly, for those with depression, or dementia conditions, they may have problems in communicating with GPs, nurses, and therapists, etc., since their cognitive abilities are impaired.

People's capability level could possibly indicate their need for healthcare services. Several studies have reported an association between lower grip strength and higher subsequent risk of fracture, and a similar trend also exists for "walking speed", "chair rises" and "standing balance" (Albrand *et al*., 2003; Cawthon *et al*., 2008). There is some evidence (Table 2.7) to suggest that objective measures of physical capability may be predictors of subsequent health in older community dwelling populations (Cooper *et al.*, 2011).

Table 2.7 Summary of main findings from review of studies that examine the associations between objective measures of physical capability levels and subsequent specified health outcomes (Cooper *et al.*, 2011).

Measure of physical capability	Outcome			
	Fracture	Cognitive decline	Cardiovascular disease	Hospitalisation and institutionalisation
Grip strength	++++eee−−	+++	++−	e
Walking speed	++++−	++	++	++−
Chair rises	+++−	e	+−	e
Standing balance	+++e−	+−		+

Note: Each indicator shown in the table represents one study population. The + indicates that there was evidence that poorer performance on the specified test was associated with increased risk of the specified outcome. e indicates an equivocal association, i.e. evidence of association was only weak or was attenuated after adjustments. The - indicates that there was no evidence of association.

This research mainly focuses on the relationship between capability loss and health conditions. We may know people's health conditions through their capabilities, and vice versa. However, there are few studies on how people's capability loss impacts on their possibility to access healthcare. If we can identify patients' capability-related needs along their care journeys, we may be able to improve their healthcare experience by designing healthcare services that are more accessible. To achieve this, it is necessary to know the level of people's capabilities, and to understand people's experience of accessing care. The holistic and available population capability data in the UK is introduced in the next section (2.4.1.4), and the concept of patients' healthcare experience and related topics are introduced in Section 2.4.2.

2.4.1.4 Data on capability variation

The 1996/1997 Disability Follow-up to the Family Resources Survey (DFS) remains the most recent Great British dataset to cover all types of ability losses that may be relevant to using everyday products or services (Johnson, Clarkson and Huppert, 2010). Specifically, the DFS was commissioned to measure the prevalence of disability among the UK population improve planning for welfare support. Multi-stage stratified random sampling and stratified clustered probability sampling were used as sampling procedures. A total of 7144 people was interviewed and answered up to 300 questions relating to 13 ability categories concerning their ability to conduct different everyday tasks, for example, "can you pick up a safety pin with your left hand?". Although the survey was not intended to estimate capabilities, it included ability categories on 'seeing', 'hearing', 'intellectual function', 'communication', 'locomotion', 'reach & stretch', and 'dexterity', which are relevant to product and service interaction. For each ability category, there were corresponding scales that divided the impairment into different levels. The answers of those participants and their corresponding severity of quality of life impairment were made available to the public (Department of Social Security, 2000).

Waller *et al.* (2013) reorganised the original answers of DFS to create new scales to measure five capability categories described in Section 2.4.1.1: *vision, hearing, thinking, reach & dexterity* and *mobility.* The survey data indicated that 18.5 % of the population have less than full capability in one or more categories. 5.3% of the population have a severe capability loss of some kind. For *vision*, a severe loss corresponds to not being able to recognise a friend at arm's length and *serious hearing loss* refers to not being able to follow a TV programme with the volume turned up. 13.2% of the population have moderate capability loss. With *moderate vision reduced*, people have difficulty in reading ordinary newsprint, while *hearing* corresponds to difficulty following a conversation against background noise. The newly

defined scales could be used to estimate the number of people who would be excluded from a product or service with a particular set of demands. More details about assessing demands using defined scales can be seen in Section 2.3.2.3, assessing demand and exclusion of healthcare services.

2.4.2 Healthcare experience

Patients' healthcare experiences constitute a broad concept. The differences among similar ideas (satisfaction and expectation), and the specific scope of this research (healthcare experience about accessing service) are defined below. In addition, care journeys and hierarchical task analysis are used to identify patients' healthcare experiences and potential needs for improvement.

2.4.2.1 Definition

Patients' experience, satisfaction and expectation are often used without clear definitions of each or how these terms interact in the setting of healthcare. People's healthcare experiences are their direct, personal observations of their healthcare which can refer to the whole of the event, or a set of steps the people go through to access and use healthcare services. People's healthcare expectations have been defined as the anticipation that given events are likely to create during or as an outcome of healthcare (Bowling, Rowe and McKee, 2013), while people's satisfaction is defined as their evaluation of what happened during healthcare (*i.e.*, evaluations of their 'experiences' of healthcare).

In summary, what people expect to receive from their healthcare ('expectation'), compared with their observations of what they receive in practice ('experiences'), are potentially important in influencing patients' evaluations of their care ('satisfaction'). The relationship between these concepts can be simply seen in Figure 2.22. In this research, we mainly explore patients' experience regarding access to healthcare services.

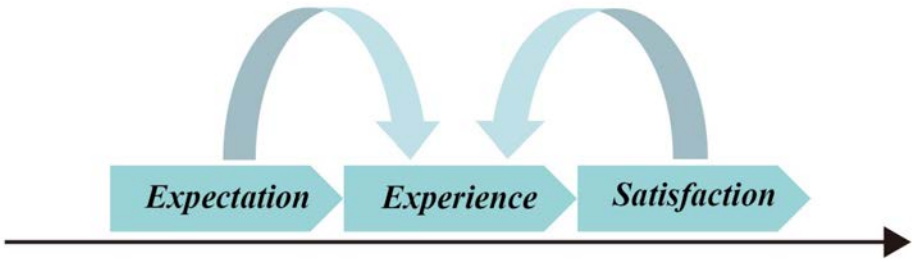


Figure 2.22 The relationship between people's satisfaction, experiences, and expectations

2.4.2.2 Healthcare experience of accessing services

To understand a patient's experience of accessing healthcare services, first and foremost it is necessary to map the care journey that the patient goes through. As mentioned in Section 2.3.3, a patient's care journey refers to the process that he or she undergoes in order to receive care. In contrast to care pathways (Section 2.3.3.1) which are relatively more universal and standard, a care journey varies from person to person since patients may have different care contexts even though they may have the same condition. Therefore, it is important to specify care journeys and select the most representative care journeys that could possibly help understand the care system's demands placed on patients' capabilities and thus identify patients' potential needs.

With a deeper understanding of the healthcare services, the detailed care journeys that patients experience in accessing the services could be more easily identified. For example, from Figure 2.15, we know that COPD diagnosis could be broken down into four steps: make an appointment with a GP; go to the GP Practice; have a GP consultation; and obtain diagnosis. In addition, there are four options for making an appointment with a GP: by telephone, by computer, by dropping in or by booking through others. Making an appointment by telephone can be further broken down into the following steps: make a telephone call, request an appointment, agree on details and mark in diary (Figure 2.23).

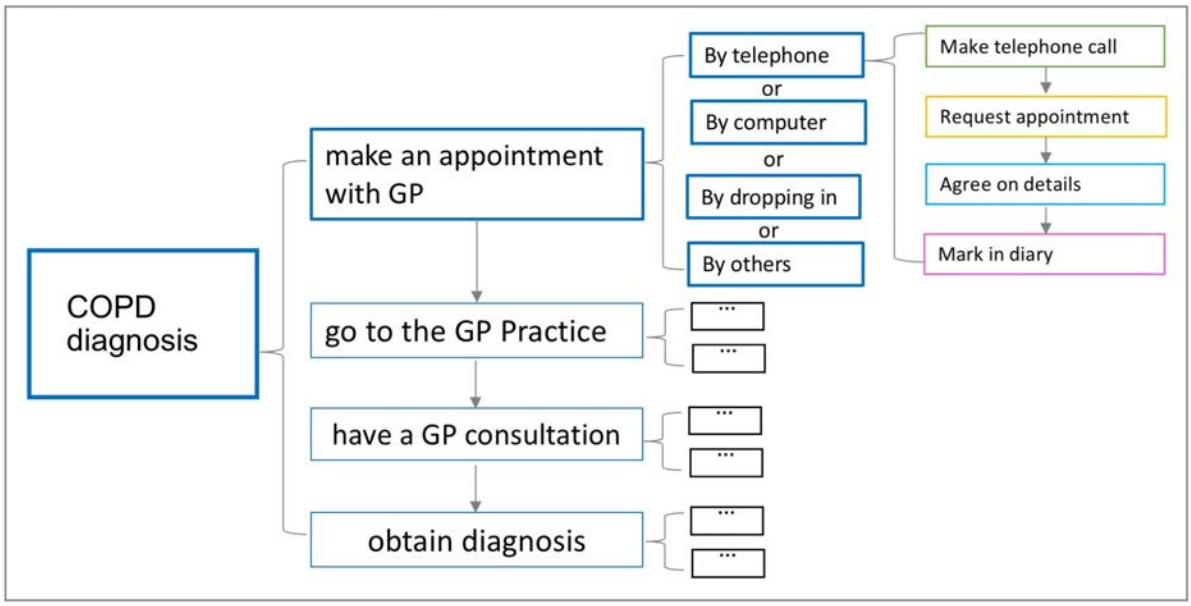


Figure 2.23 An example of a care journey represented in a hierarchal task analysis

Once the tasks along the care journeys are identified and organised in a hierarchical way, we are able to assess the demand of each task as well as the whole care journey using the assessing demand and exclusion method introduced in Section 2.3.2.3.

To improve patients' experience of accessing healthcare services and reduce exclusion, it is important to involve patients in managing their conditions, especially those people with long-term conditions. The details about patients' self-management of long-term conditions are introduced in Section 2.4.3.

2.4.3 Self-management of long-term conditions

To empower people to self-manage chronic diseases at home and avoid unplanned hospital admission is one of the targets within the community-based care context. The definition of self-management, the process that people experience who live with chronic conditions, and the support that patients need to access community-based healthcare services that can help them better self-manage chronic conditions are discussed below.

2.4.3.1 Self-management

Self-management refers to a range of approaches that aim to enable people living with long-term conditions to manage their own health effectively (NHS England, 2017b). As experts in their own lives, people gain the skills and knowledge to cope as best they can with their own long-term condition/s. Patients have reported increases in physical functioning, benefits in terms of greater confidence and reduced anxiety since their actively involved self-management (Challis *et al*., 2010; de Iongh, 2014). Self-management programmes have been shown to reduce unplanned hospital admission for chronic obstructive pulmonary disease (COPD) and asthma (Purdy 2010) and to improve adherence to treatment and medication (Challis *et al*., 2010).

Despite the advantages of self-managing long-term conditions, it is not easy for people to adapt to and live with changes. Therefore, it is important to understand the process that people with long-term conditions typically undergo and thus offer support to encourage people to engage in self-care in the community.

2.4.3.2 The process that people live with long-term conditions

People have to make a series of adjustments to their lives when they are diagnosed with a long-term condition. Corben and Rosen (2005) from the Kings' Fund highlighted three topics that are particularly important in shaping people's responses to living with long-term conditions: i) the different ways in which people receive their diagnosis; ii) the fact that different people have different responses; iii) the fact that people's ability to self-manage changes over time. Specifically, receiving a diagnosis of a chronic condition is the first step for people to begin to adjust to their lives. For some diseases such as diabetes and arthritis, the diagnosis is

straightforward, while for some diseases like Parkinson's disease it may take longer to obtain a definitive diagnosis, and some diseases like COPD may be unfamiliar to people and people may feel anxious about the diagnosis. Therefore, it is vital to make sure patients have enough information when they are diagnosed with a long-term condition and encourage them to manage it. In fact, there are many factors, e.g., severity of disease, age, social and family support, and level of education that could possibly impact on whether or not a person would actively participate in self-management (Gordon and Rice, 2015). Not all people want to - or can - self manage a long-term condition. An individual's involvement in self-management is likely to change over time: it may increase but it may also decrease. Most people find a way to live with the condition, although the level of self-management may differ.

2.4.3.3 Patients-centred support for self-managing long-term conditions

Understanding what is important to patients is vital to support them to manage their chronic conditions. Self-management is hard work and patients need to acquire the knowledge and skills to live with their conditions (Coulter, Roberts and Dixon, 2013). The need for patients to have clear information about their condition and guidance on how to access it is essential to support self-management (Corben and Rosen, 2005). From the point of diagnosis or even before, people are faced with various different healthcare services and many have little idea of how to choose between them. Patients need support to understand their conditions and to know the available services that can help them. However, people are unlikely to be given much information about their conditions when first diagnosed, although information is needed in many formats, and as early as possible (Hussein and Partridge 2002). Meanwhile, the GP is often the first professional that patients contact and thus whether the GP can signpost the appropriate healthcare professionals to patients depends on the GP's knowledge and experience. In fact, the patients would be better cared for and the burden on GPs could be lessened through other care co-ordinators such as nurses and volunteering support groups.

In this research, the support for self-management mainly refers to the support that can help patients access suitable community-based healthcare services and thus achieve self-management of their long-term conditions. Clear, accessible information and signposting is the key to patients' access to suitable healthcare services.

To summarise Section 2.4, people's capabilities change mainly due to their age and conditions, and people's reduced capabilities influence their possibility to access healthcare services. By estimating community-based healthcare services' demands on patient's capabilities, we are able to identify the most challenging tasks for patients along their care journeys, understand

their capability-related needs and make the service more accessible. This is particularly important for people living with long-term conditions since people are more likely to self-manage their condition in familiar places, i.e., home or within the community, instead of being admitted to hospital.

2.5 Summary

Inclusive Design and its associated tools have been widely applied to consumer products and services which are tangible. However, there is little evidence of research that applies Inclusive Design to healthcare services which are less tangible. In fact, the procedures for applying Inclusive Design, e.g., mapping user journeys and task analysis, as with many service design methods, treat the services as tangible, which is the reason why Inclusive Design is potentially applicable to healthcare services. Therefore, the research aims to fill this research gap and explore how Inclusive Design can be applied to healthcare delivery services to improve patients' experience of accessing these services. Specifically, the research focuses on patients' experiences of accessing community-based care, i.e., it aims to provide care at or closer to home and is a preferred choice to meet the healthcare demand for long-term conditions among an ageing population. What makes Inclusive Design distinct from other approaches is the possibility of using an *Exclusion Calculator* to estimate the exclusion across a range of capabilities. By understanding community-based services' demands on people's capabilities along their care journeys, we are able to identify patients' capability-related needs and help as many people as possible to access the services. The next chapter is about the research methodology of this research.

3 Research Methodology

The literature reviewed in Chapter 2 highlights the lack of evidence for how Inclusive Design can be applied to community-based healthcare services to improve patients' experience of accessing these services.

This chapter presents an overview of the research process with regard to the research paradigm, research questions, methodology, data collection methods and data sources. The ethical considerations are also explained.

Figure 3.1 demonstrates the structure of Chapter 3 and how previous chapters inform and influence this chapter. Chapter 1 introduces the research questions that are justified by the research motivations and highlights gaps in the literature identified through the literature review (Chapter 2). Section 3.1 discusses the research paradigm which influences the research questions (Section 3.2), and the research methodology (Section 3.3) that is used to answer the questions. Section 3.2 reviews the research questions that motivated the selection of a research methodology (Section 3.3). Section 3.4 presents the research methods used, which aim to provide evidence for the research questions. The selection of case studies and related research ethics are discussed in Section 3.5 and Section 3.6 respectively.

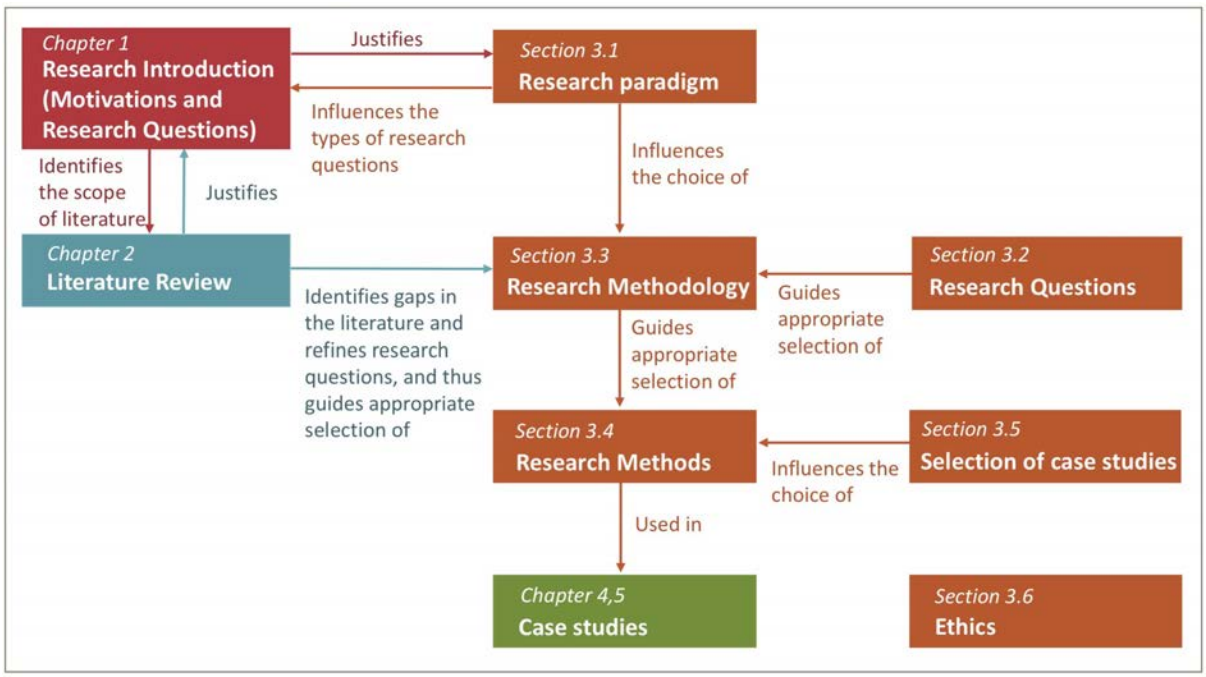


Figure 3.1 The structure of Chapter 3: Research Methodology

3.1 Research paradigm

The word "paradigm" was first used by Thomas Kuhn as a term to describe new ways of thought that could revolutionise knowledge and therefore become new accepted ways of thinking and doing (Kuhn, 2012). Later, Guba (1990) defined the term paradigm in its most common form: "a basic set of beliefs that guide action". He claimed that "paradigms are the starting point or givens that determine what inquiry is and how it is to be practiced", whilst acknowledging that these belief systems or paradigms are 'human constructions' and therefore, "subject to all the errors and foibles that inevitably accompany human endeavors".

Before introducing the different types of research paradigms, it is necessary to understand the characteristics that decide the classification. Generally speaking, research paradigms are classified by their characteristics in terms of ontology, epistemology and methodology. Ontology is about what exists, or what there is to know (Hay, 2002). Epistemology is about 'how what is assumed to exist can be known' (Blaikie, 2000). Methodology is concerned with the logic, potentialities and limitations of the inquiry, which relates to 'how [we can] go about acquiring that knowledge' (Grix, 2002). Figure 3.2 below defines the above terms and the relationship between them:

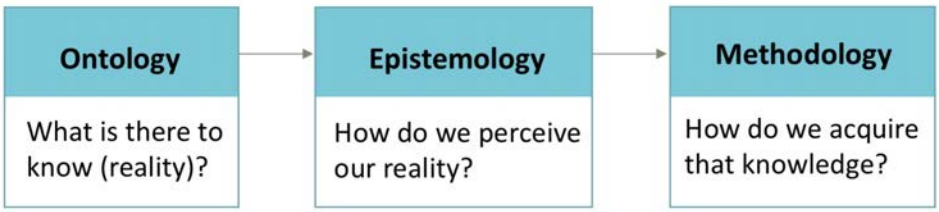


Figure 3.2 The relationship among ontology, epistemology and methodology, adapted from Hay (2002)

Guba (1990) classified research paradigms into four categories: *positivism, post-positivism, critical theory* and *constructivism* (summarised in Table 3.1). Specifically, *positivism* is based on the belief that reality exists and is driven by natural laws (ontology). As Guba described, the nature of science is to "discover the 'true' nature of reality and how it 'truly' works." The positivist is committed to a realist ontology and is restricted to an objectivist epistemology. In terms of methodology, the positivist adopts a manipulative methodology in which questions are subjected to empirical tests, to ensure decisions follow the laws of nature. *Post-positivism* is a modified version of the positivist stance that acknowledges human frailty, which makes it impossible for humans to perceive reality fully. Therefore, *post-positivism* emphasises critical realism, modified objectivism as well as experimental/manipulative methodology. Although *Critical theory (ideologically oriented inquiry)* moves to a subjectivist epistemology, it still keeps the critical realist ontology of *post-positivism*. In contrast to *critical theory,*

constructivism proposes relativism and believes 'reality' only exists in the context of a mental framework. It claims that our perception of knowledge is relative to the way we understand and construct it and our sense of 'reality' may change along with this understanding and construction. In terms of methodology, *critical theory* takes a dialogic approach that aims to eliminate false consciousness, and *constructivism,* which contains hermeneutics and dialectics, aims to create open knowledge construction so that information can continue to be enhanced.

Table 3.1 Characteristics of research paradigm adapted from (Guba 1990)

Paradigm Classification	**Paradigm Characteristics**		
	Ontology	*Epistemology*	*Methodology*
Positivism	Realist	Objectivist	Experimental/manipulative
Post-positivism	Critical realist	Modified objectivist	Modified experimental/ manipulative
Critical theory	Critical realist	Subjectivist	Dialogical, transformative
Constructivism	Relativist	Subjectivist	Hermeneutic, dialectic

Regarding the paradigm of this research, it seems to fit more closely with the less objective paradigms (*post-positivist, critical theory*, or *constructivism)* based on Guba's classification of paradigm, since the overarching research question is 'How can Inclusive Design be used to improve access to healthcare services in the community?'. Specifically, the research aims to apply Inclusive Design to improve patients' experience of accessing healthcare services, which relies on collecting data about patients' personal views and perceptions. As a result, this research does not match the positivist stance that emphasises the value free aspect. The ontological stance is similar to 'critical realism'(belong to *post-positivism* and *critical theory*) which acknowledges the reality of natural order but recognises that this can only be known imperfectly due to the limitations of the researcher. In addition, the Inclusive Design approach to improving patients' access to healthcare services is required to collect the truth related to two aspects. One relates to the definition of the levels of demand healthcare services place on patients' capabilities, which seems to fit a relativist stance as the levels of demand exist in humans (mental framework); the other relates to the level of patients' capabilities, which relates more to critical realism as it is difficult for humans to fully perceive their own capabilities. Therefore, the paradigm of this research cannot be solely defined according to one classification in relation to Guba's paradigm theory.

In contrast to Guba's definition of critical realism which emphasises the limitations of the researchers, Robson and McCartan (2016) introduced a pragmatic approach to *realism* that provides social research with scientific characteristics. Robson's *realism* not only provides a useful language with which to answer 'how' or 'why' questions, but also provides a way of approaching open and uncontrolled situations to ensure the findings are directly related to the researched situations. *Realism* can provide a model of scientific explanation free of the problems encountered in positivist and relativist accounts. *Realism* has been seen as particularly appropriate for research in practice-based and value-based professions such as social work (Anastas, 1999), which matches the context of this research, i.e., improving services and patients' experience of accessing healthcare services.

Along with the idea *realism*, Robson proposes a concept of *real world research*, which refers to relatively small-scale research carried out by individuals or small teams and aims to 'understand the lived-in reality of people in society and its consequences'. He advocates pragmatically selecting ideas from different realist approaches that can be useful to real world research. In a sense, *realism* is a type of pragmatism, which is almost an 'anti-philosophical' philosophy. This does not mean that establishing a philosophical stance is of no value. Instead, it tends to focus on which questions are important to study and which methods are appropriate for finding answers. To some extent, Guba's concept of research paradigms has been transferred from 'philosophical stances' to 'shared beliefs among groups of researchers' (Morgan, 2007) and it is essential to understand Guba's paradigm to better position the research paradigm.

In summary, *realism* according to Robson's interpretation, which adopts a pragmatic approach and a scientific attitude to real-world problem-based research, is in accord with this research context. The next section reviews the research questions, which inform the research methods and methodology in later sections.

3.2 Research questions

It is important to review the research question at this stage (after analysing the research paradigm and before introducing the research methodology). Crotty (1998) proposed two approaches, the top down approach and the bottom up approach, to decide where research sits. According to Crotty, the two approaches are defined based on four elements, i.e., methods, methodology, theoretical perspective, and epistemology, which are included in any research process. Specifically, *methods* refer to the techniques or procedures used to collect and analyse

data to answer research questions. *Methodology* encompasses the strategy used to choose particular methods and links the choice of methods to the desired outcomes. *Theoretical perspective* informs the methodology and provides a context for the process and grounding of its logic and criteria, i.e., how we know what we know. *Epistemology* is the theory of knowledge embedded in the theoretical perspective. Crotty's categorisation does not include ontology, although he mentions that ontology would sit alongside epistemology to inform the theoretical perspective. In the bottom up approach, a review of the research questions can inform the methods, which in turn could inform the methodology, and subsequently the theoretical perspective, which would thus inform the epistemology. The process is more like a deconstruction of the research question. The top down approach is the opposite.

This research is neither strictly the deduction (bottom up) nor induction (top down) approach, as it requires the researcher to go up and down to find a pragmatic approach to the research. Therefore, the research process (see Figure 3.3) suggested by Sim and Wright in their book 'Research in Health Care' (Sim and Wright, 2000) is used in this research. A review of the research questions can provide clues for choosing an appropriate research methodology, and thus result in a better design for the research.

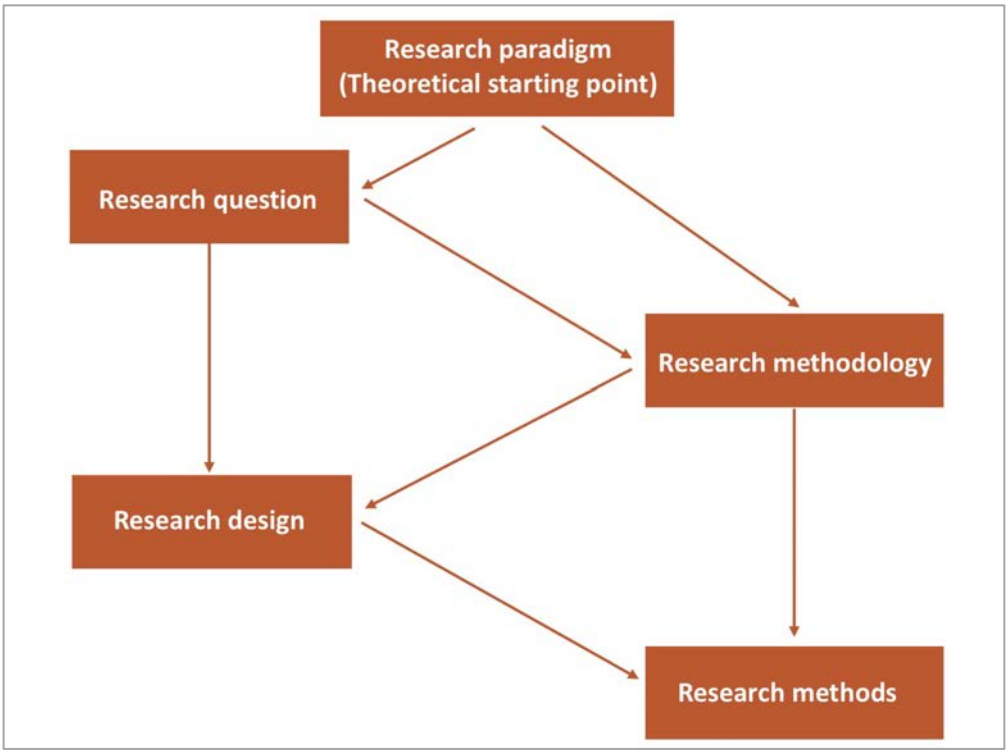


Figure 3.3 The relationship between research paradigm, question, methodology, design and methods, adapted from Sim and Wright (2002)

The overarching research question is repeated here:

How can Inclusive Design be used to improve access to healthcare services in the community?

A set of questions derived from the main research question is needed to justify the significance of the research and facilitate the data collection. Specifically, the three research questions (RQ1-RQ3) below explore evidence from the literature review (Chapter 2) suggesting that Inclusive Design can possibly be an approach to addressing healthcare services' challenges for an ageing population.

- Sub-RQ1 What is the state-of-the-art understanding and application of Inclusive Design?
- Sub-RQ2 What are the challenges of an ageing population associated with community-based healthcare service delivery?
- Sub-RQ3 To what extent do people's capabilities affect their access to community-based healthcare services?

While Sub-RQ1 & RQ2 are more about understanding the research context and are based solely on the literature review, Sub-RQ3 relates to people's capability, so no database can be used directly. Therefore, Sub-RQ3 requires further clarification. Although evidence from the literature review indicates that people's capability could affect their access to healthcare services, data on patients' capability and the delivery of healthcare services are still needed to answer the question. The other two research questions (RQ4 and RQ5) below focus on the application, advantages as well as limitations of Inclusive Design in improving people's access to healthcare services.

- Sub-RQ4 How can we use the principle of Inclusive Design to improve people's access along the care journey?
- Sub-RQ5 What are the advantages and limitations of Inclusive Design as a means of improving people's access to healthcare services in the community?

Since different long-term conditions may have various care pathways and patients' care journeys are diverse, it is impossible to cover all the care pathways of community-based care. Therefore, in order to narrow down and specify the research scope, it is important to limit the care journeys that are explored. Two case studies of community-based rehabilitation services related to back pain and chronic obstructive pulmonary disease (COPD) were conducted to explore the use of Inclusive Design to increase people's experiences of accessing healthcare.

The case studies provide first-hand evidence to answer sub-research questions 3, 4, and 5. The reason for choosing these two conditions will be introduced in Section 3.5. The specific research questions for these two case studies and their link with sub-questions 4 and 5 are presented in Figure 3.4.

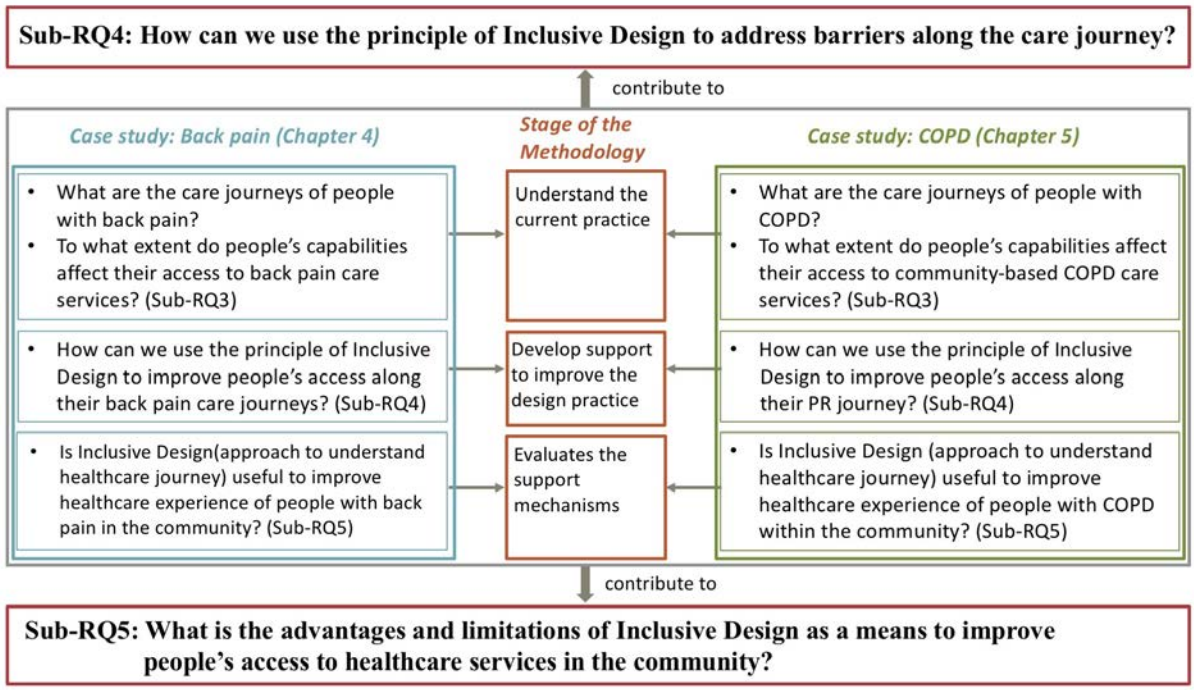


Figure 3.4 Research questions of the two case studies and how they inspire the research methodology

The specific research questions can also inspire the choice of research methodology (see Figure 3.4). In the case study related to back pain, the questions '*What are the care journeys of people with back pain?*' and '*To what extent do people's capabilities affect their access to back pain care services?*' require the collection of data on healthcare services and patients' capabilities to understand the current practice. The question '*How can we use principle of Inclusive Design to* improve people's access *along the back pain care journey?*' is required to develop support mechanisms to improve the design practice. The last question '*Is Inclusive Design (approach to understand healthcare journey) useful to improve healthcare experience of people with back pain in the community?*' evaluates the support mechanisms. The next section presents and criticises the research methodology in this research.

3.3 Research methodology

Methodology refers to the general principles of investigation that guide a study, which are based on its underlying theoretical and philosophical assumptions. It is the overall approach to

the research (Sim and Wright, 2000). An appropriate research methodology ensures that research is conducted scientifically, i.e., the results of the research have validity in some generic, theoretical as well as practical sense (Blessing and Chakrabarti, 2009).). Since this research project is multidisciplinary and includes users (patients), design, and healthcare services, it draws not only on research methodologies, but also on design methodologies (See Table 3.2).

Table 3.2 The list of methodologies

	Origin and Name	Aims	Contents
Research Methodologies	**A five-stage framework for research design (Robson, 2016: p72)**	A framework contains simple components that guide a research project	Purpose(s); Conceptual framework, Research questions, Methods, Sampling procedures
	Design research methodology (DRM)framework (Blessing and Chakrabarti, 2009)	A framework offers stepwise, hands-on approach to design research	Research Clarification (RC), Descriptive Study I (DS-I), Prescriptive Study (PS), Descriptive Study II (DS-II)
	Spiral of applied research (Eckert, Clarkson and Stacey, 2003)	A framework guides design research that is carried out in large research teams	Empirical studies of design behaviour, Evaluation of empirical studies, Development of theory, Evaluation of theory, Development of tools and procedures, Evaluation of tools and procedures, Introduction of tools and procedures, Evaluation of dissemination
Design Methodologies	**Design wheel model (Waller *et al.*, 2015)**	A model guides the process of concept design	Manage, Explore, Create and Evaluate
	Double diamond diagram (Design Council, 2005)	A simple graphical way of describing the design process	Discover, Define, Develop, and Deliver

Specifically, this research mainly adopts the Design Research Methodology (DRM) framework, since it covers most of the contents of the *five-stage framework* and the *spiral of applied approach*, and more importantly, it has also been recommended as a suitable framework for a design-based PhD project (Blessing and Chakrabarti, 2009). The other two models, i.e., *Double Diamond* and *Design Wheels* are also consulted in this research. The details are discussed below.

1) DRM-Design research methodology framework

DRM was first developed by Blessing and Chakrabarti together with Professor Ken Wallace at the Cambridge Engineering Design Centre (EDC) in 1991. Since then, DRM has undergone

continuous enhancement as documented in several publications (*e.g.*, Blessing, Chakrabarti and Wallace,1992 and 1995) and finally, as summarised in a textbook by Blessing and Chakrabarti (2009). It helps researchers identify research topics and select suitable methods to address the issues at hand. It consists of four stages: Research Clarification (RC), Descriptive Study I (DS-I), Prescriptive Study (PS) and Descriptive Study II (DS-II). Figure 3.5 shows the links among these stages, the basic means used in each stage, the main outcomes, and the deliverables within this framework.

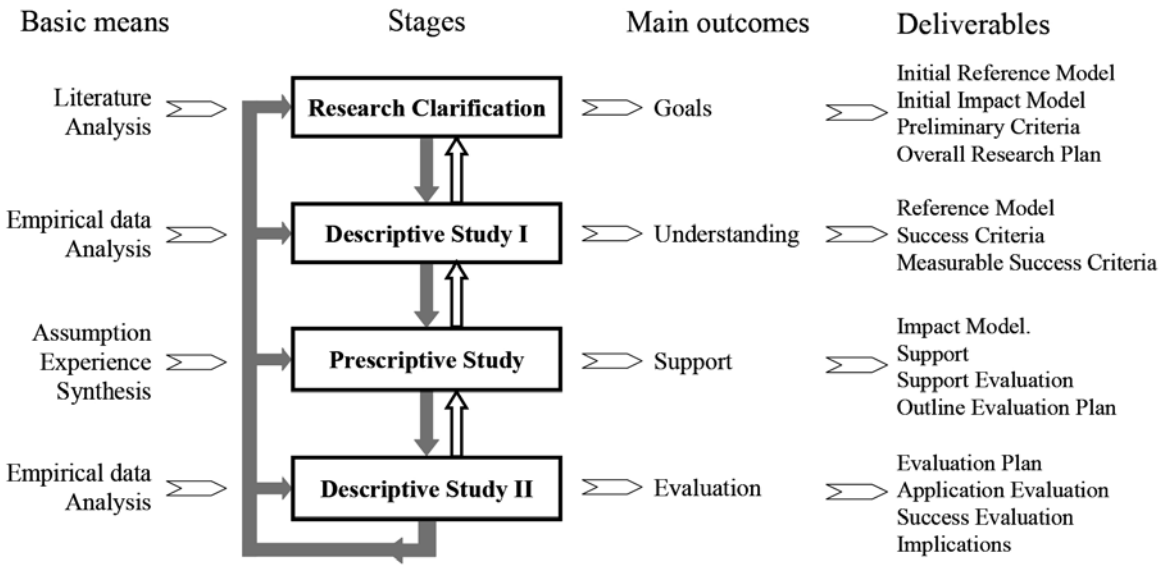


Figure 3.5 The DRM framework
Source: Adapted from Blessing and Chakrabarti (2009)

i)The *Research Clarification* stage is concerned with defining the research goal, an initial description of the existing and desired situation, and the formulation of criteria to measure the outcomes of the research. The main deliverable of this stage is an overall research project plan.

ii)The *Descriptive Study I* stage deals with the literature review and/or empirical studies to provide an initial description of the existing situation and to increase understanding of the research problem. The role of this stage is to identify factors that influence the measurable success criteria and to establish state-of-the-art criteria on the basis of what support can be developed to improve the design practice.

iii)The *Prescriptive Study* stage deals with the development of design support tools (an impact model or theory) to describe the desired situation.

iv)The *Descriptive Study II* stage focuses on evaluating the developed support (a model or theory) in terms of whether it achieves the desired outcome. Two types of evaluation of the

developed design support are undertaken: application evaluation and success evaluation. The former assesses whether the support can be used in the situation for which it is intended, and the latter assesses the usefulness according to the success criteria.

Blessing and Chakrabarti (2009) acknowledge that it is unlikely for one research project to include each DRM stage or undertake each stage to an equal extent. Figure 3.6 lists the seven possible types of design research by considering whether a particular research stage requires a review-based, comprehensive or initial study. The research questions, hypotheses, available resources and time affect the types of research. A review-based study only focuses on a literature review, while a comprehensive study includes a literature review and other results (i.e., from an empirical study), develops support, or evaluates support produced by the researcher. An initial study provides initial results which can be used by other researchers (Blessing and Chakrabarti, 2009).

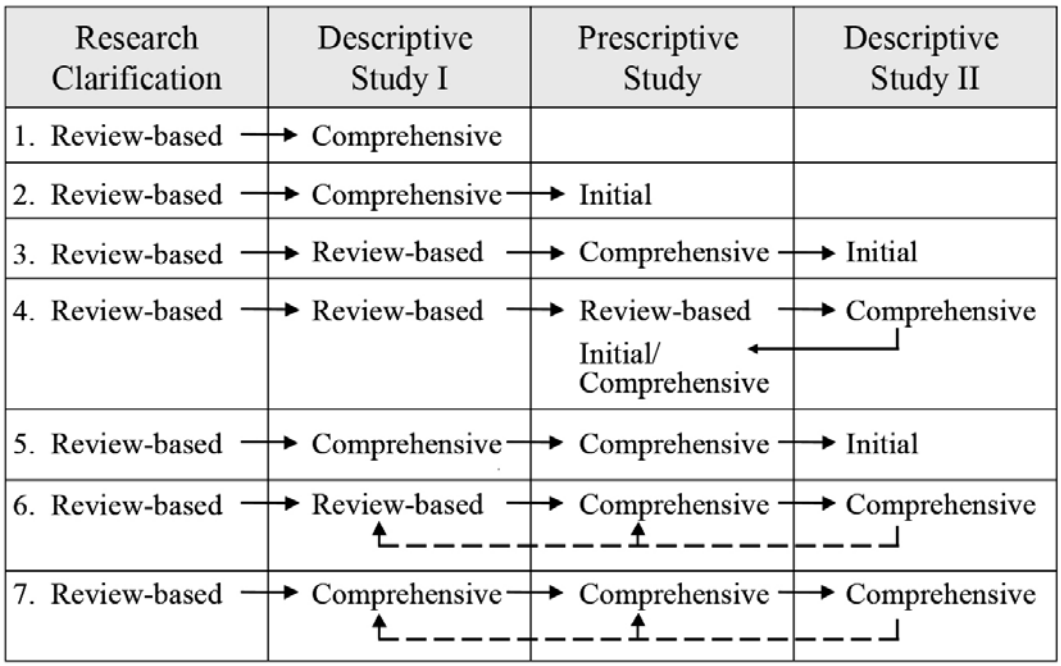


Figure 3.6 Types of design research projects and their main focuses (Blessing and Chakrabarti, 2009)

The first four types of research projects are recommended for PhD work (Figure 3.7). Projects of types 5 and 6 are highly desirable but often unattainable in PhD projects due to time and resource constraints. Type 7, which is the only type with three comprehensive studies, is more common for joint efforts undertaken by a research group. In terms of this PhD research, it aims to achieve type 3 (Figure 3.7) which includes a literature review, case studies, support development of design and initial results that can be used by other researchers.

Research Clarification	Descriptive Study I	Prescriptive Study	Descriptive Study II
1. Review-based	Comprehensive		
2. Review-based	Comprehensive	Initial	
3. Review-based	Review-based	Comprehensive	Initial
4. Review-based	Review-based	Review-based Initial/ Comprehensive	Comprehensive
5. Review-based	Comprehensive	Comprehensive	Initial
6. Review-based	Review-based	Comprehensive	Comprehensive
7. Review-based	Comprehensive	Comprehensive	Comprehensive

Target of this PhD work

Figure 3.7 The research type of DRM framework

2) The Double Diamond diagram

The Double Diamond diagram (Figure 3.8) was developed by the Design Council (2005) as a simple graphical way of describing the design process. Divided into four distinct phases (*i.e.*, Discover, Define, Develop, and Deliver), it maps the divergent and convergent stages of the design process.

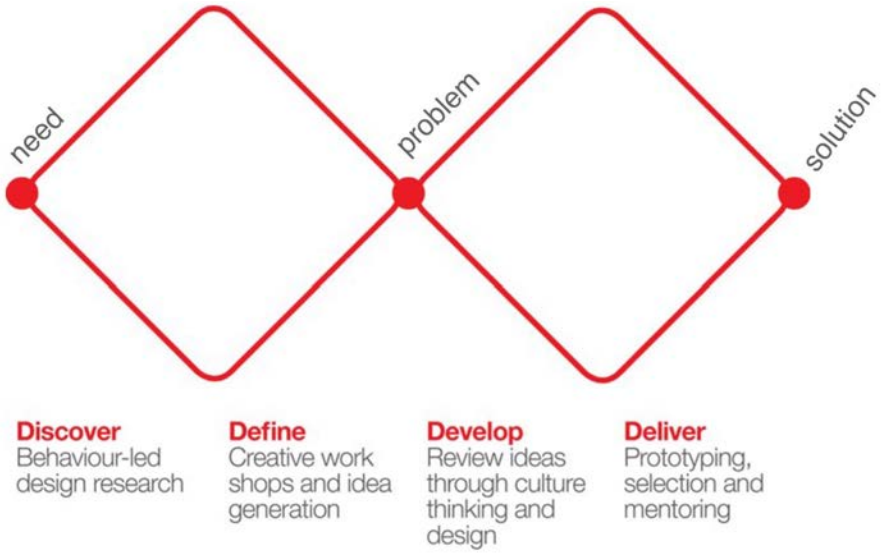


Figure3.8 Double Diamond model (Design Council, 2005)

The Double Diamond design process model was devised to support the transformation of needs into design ideas and then products or services for companies rather than planning a PhD study. However, this graphical way of mapping the design process can be used to represent research progress in this research.

3) The Design Wheel model

The Design Wheel model (Figure 3.9) describes the four main elements of concept design: Manage, Explore, Create and Evaluate. Successive cycles of Explore, Create and Evaluate are used to generate a clearer understanding of the needs, better solutions to meet these needs and stronger evidence that the needs are met (Waller *et al*., 2015). The model is particularly useful in supporting concept design and giving enhanced prominence to rapid iteration and early-stage evaluation. In addition, it is embedded with many Inclusive Design tools, e.g., an exclusion calculator, which can be used to estimate the services' demand on people's capability and the exclusion number in this research.

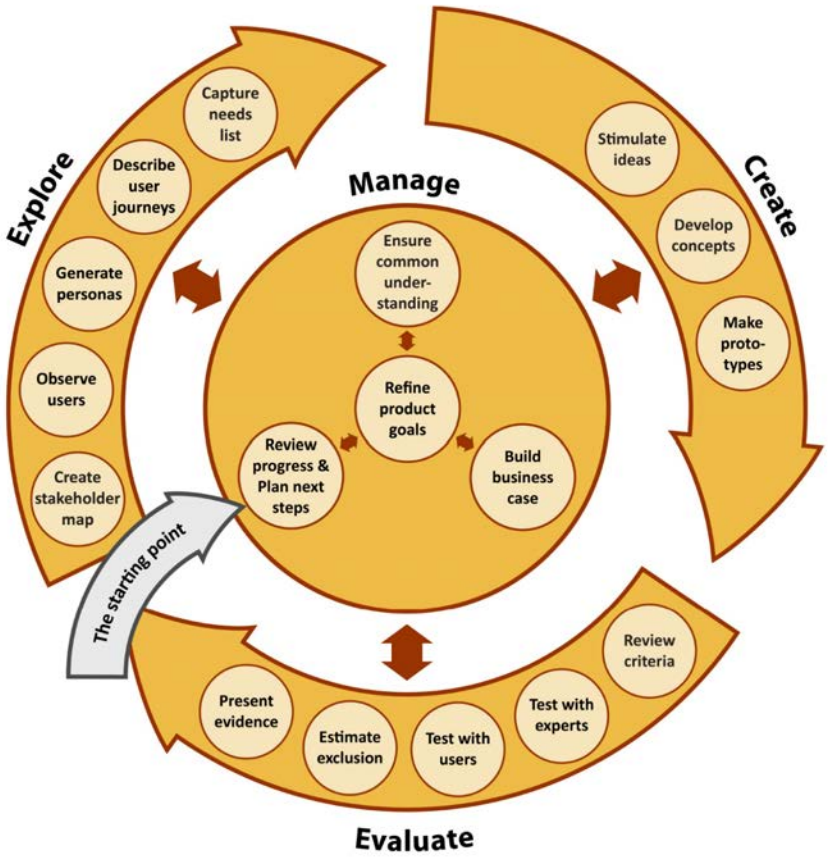


Figure 3.9 Design Wheel (Waller *et al*., 2015)

By analysing the *DRM* framework, *Design Wheel*, and *Double Diamond*, it can be seen that they are naturally similar design processes in design research (Figure 3.10), i.e., exploring to define the needs, understanding to identify the problem, creating the solution to support and evaluating to validate the support, although each model is suitable to different scenarios. The main approach of this research is based on the DRM framework, with some flexible adjustments and research tools drawn from the Double Diamond and Design Wheel (Figure 3.11). Specifically, the research methodology framework for this research is divided into four stages: *Research Clarification* (RC), *Descriptive Study I* (DS-I), *Prescriptive Study* (PS), and

Descriptive Study II (DS-II). It is based on the DRM framework but is presented in a similar way to that of the double diamond model since the double diamond model can visually show the divergent and convergent stages of the design process. The dashed line in Figure 3.11 shows the PhD methodology target, i.e., to undertake an empirical study, develop or evaluate support, and prepare the results for use by others (matched with the PhD target, i.e., type 3 of the DRM framework which was shown in Figure 3.7).

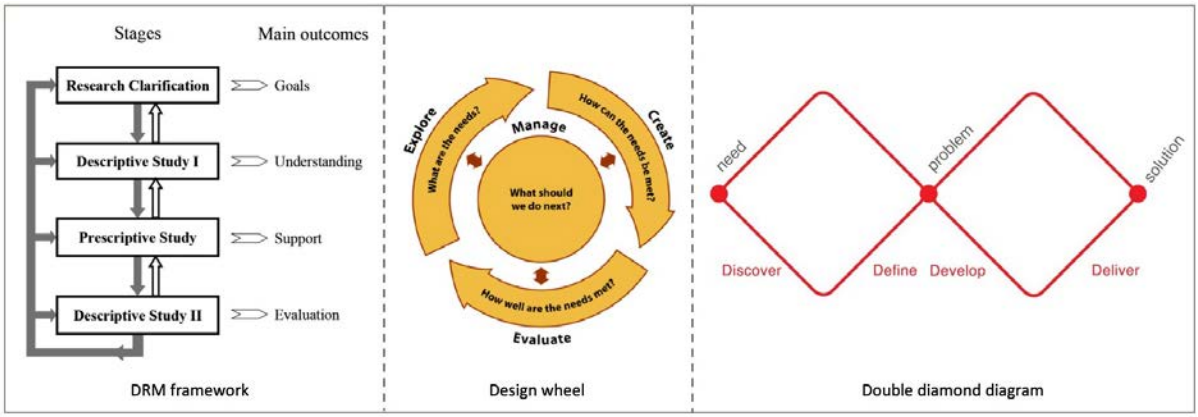


Figure 3.10 DRM *vs.* Design Wheel *vs.* Double Diamond

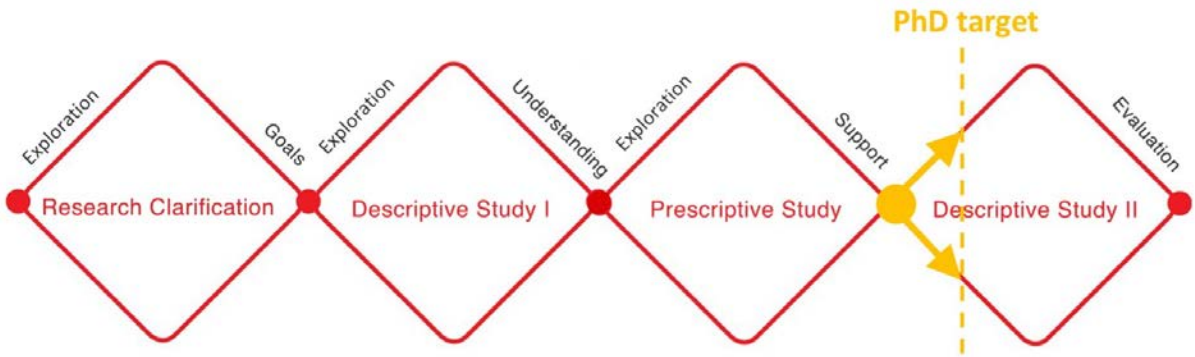


Figure 3.11 The research methodology framework

Table 3.3 presents a brief description of how this research methodology framework is applied to guide the research on how Inclusive Design can be used to improve access to healthcare services in the community. Based on the research clarification (Stage 1: RC), key factors impacting on service improvement and criteria for measuring success are identified (Stage 2: DS-I), and an inclusive healthcare service approach as well as recommendations are proposed (Stage 3: PS) and evaluated (Stage 4: DS-II). Based on this defined research methodology framework, the research methods are selected and introduced in the next section.

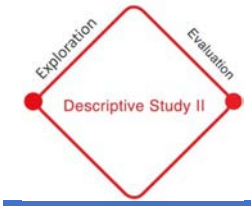
Table 3.3 Application of the overall research methodology for this research

Steps of different Research Methodology stage	Description
Stage 1: *Research Clarification* (RC)	
1.1 Research focus and goal	The challenges associated with healthcare service delivery in an ageing population create a potential research opportunity and goal for Inclusive Design, i.e., how to improve people's access to healthcare services by understanding the service's demand on people's capability.
1.2 Research problem and question	In the literature, there is little evidence of applying Inclusive Design to healthcare services. The research question is "*How can Inclusive Design be used to improve access to healthcare services in the community?*"
1.3 Relevant areas	Inclusive Design, Healthcare services, Patients (User-centred research)
1.4 Criteria to measure outcomes	Success is measured by the experiences of potential users
1.5 Expected contribution	i) The evidence of how Inclusive Design can be used in improving healthcare services. ii) An inclusive healthcare service approach is summarised to help care providers understand community-based rehabilitation services' demand on patient's capabilities and make recommendations to improve the accessibility of these healthcare services. iii) The advantages and limitations of Inclusive Design to improve healthcare delivery (long-term conditions' rehabilitation services) are presented.
Stage2: *Descriptive Study I* (DS-I)	
2.1 Detailed existing situation and current problems	Community-based care which aims to provide care at or closer to home is a preferred choice to meet the healthcare demand for long -term conditions in an ageing population. However, the utilisation of community-based care is low. If we could understand patients' capability-related needs and improve their experience of accessing the services, more patients are likely to be included.
2.2 Key factors impact improvement	i) Map the representative and comprehensive patients' community-based care journeys; ii) Measure the community-based services' demand on patients' capabilities along their care journeys; iii) Measure patients' capability.
2.3 Completed success criteria	i) Success is measured by the experiences and comments of potential users (e.g. patients, care providers, and healthcare professionals) regarding the proposed improvements/ approach due to the limited time and resources ii) Success is also measured by the services demands on patients' capabilities based on the proposed more inclusive care pathway
Stage3: *Prescriptive Study* (PS)	
Desired situation	i) An inclusive healthcare service approach is proposed that can help care providers to understand patients' capability needs when they access to community-based care and thus make the services more inclusive. ii) To provide evidence that Inclusive Design can be used to improve the utilisation of community-based healthcare services.
Stage4: *Descriptive Study II* (DS-II)	
Evaluation of the developed support	The proposed recommendations and inclusive healthcare service approach is evaluated through focus groups with patients and a survey with healthcare professionals to make sure it is applicable and useful.

3.4 Research design and methods

A research design provides the logical structure for the research project, which is used to guide data collection and analysis in order to answer the research question in a way that is consistent with the research methodology (Sim and Wright, 2002: p27). This research was designed based on the research methodology framework summarised in Table 3.3 and the research methods listed in Table 3.4.

Table 3.4 Research methods in relation to research methodology stage, questions, and chapters

Research Methodology stages	Research questions	Chapters	Research Methods
Research Clarification 	How can Inclusive Design be used to improve access to healthcare services in the community? (main question)	Chapter 1, 2	Document analysis
Descriptive Study I 	What is the state-of-the-art understanding and application of Inclusive Design?	Chapter 2	Document analysis
	What are the challenges of an ageing population associated with community-based healthcare service delivery?	Chapter 2	Document analysis
	To what extent do people's capabilities affect their access to community-based healthcare services? (Evidence from literature)	Chapter 2	Document analysis
Prescriptive Study 	How can we use the principle of Inclusive Design to improve people's access along the care journey (back pain and pulmonary rehabilitation)? To what extent do people's capabilities affect their access to community-based healthcare services? (First-hand data)	Chapter 4, 5	Document analysis Case study (Questionnaire, Interview, Focus group)
Descriptive Study II 	What are the advantages and limitations of Inclusive Design as a means of improving people's access to healthcare service in the community	Chapter 4, 5, 6	Questionnaire, Interview, Focus group

Three main factors that were taken into account in terms of selecting appropriate methods. Firstly, it was important that the chosen methods could support the collection of data in a practical environment. The main benefit of collecting data from the healthcare industry is that the results are based on reality (Blessing and Chakrabarti, 2009: p254), which could reflect

patients' real needs. For this reason, lab-based experiments were not appropriate for this research. Secondly, it was also necessary to ensure the methods were applicable to the individual researcher, the available resources, and the research schedule. Thirdly, methods were selected based on their advantages and disadvantages compared with other methods, and how the methods complemented each other in answering the research question. A brief description of all the methods used in the research is presented below. More details about each method are given in the relevant chapters.

3.4.1 Document analysis

Document analysis refers to a systematic procedure for reviewing or evaluating documents including printed and electronic materials. Documents provide background and context, additional questions, supplementary research data, a means of tracking change and development, and verification of findings from other data sources (Bowen, 2009). More importantly, document analysis is particularly applicable to qualitative case studies, which can provide rich descriptions of a single phenomenon, event, organisation, or program (Stake, 1995; Yin, 2014).

For this research, documentary sources stemmed from various channels such as reports from the NHS and even online news. All the chapters except Chapter 7 include document analysis to provide evidence or complement data for understanding current and proposed practices. However, as a research method, document analysis is unlikely to provide the practical experience of the patients and healthcare professionals regarding how they access or provide care services. As a consequence, other research methods, such as case studies, questionnaire, interviews and focus groups are used to understand actual practice.

3.4.2 Case studies

A case study is an empirical inquiry that aims to understand a contemporary (as opposed to entirely historical) phenomenon within a real-world context. Case study research is the recommended method when the main research questions are "how" or "why" questions (Yin, 2014), which is the case with this research (i.e., the main research question is: How can Inclusive Design be used to improve access to healthcare services in the community?). Multiple sources of data are often used in case studies, including both qualitative and quantitative (Yin, 2014; Robson, 2016). It is important to clarify that case study has also been viewed as an approach, a style, a strategy or a design (Punch, 2005; Cohen, Manion and Morrison, 2007;

Yin, 2014; Bryman, 2004). This research regards case study *as a research method,* i.e., *a particular way of doing research*, and does not regard it as the main focus of the research.

In terms of this research, two case studies, i.e., one with people with back pain (Chapter 4) and one with people with COPD (Chapter 5) were conducted to provide practical evidence to address the research questions. For each case study, three categories of data needed to be collected: i) healthcare professionals' experiences and perceptions of care pathways; ii) patients' experiences and perceptions of care journeys; iii) and patients' capability data. By collecting representative data, case studies make it possible to provide evidence for research questions. The reasons why these two long-term conditions were selected as case studies and how the case studies were carried out are explained in Section 3.5.

3.4.3 Surveys

Questionnaire-based surveys were used in both case studies to contribute to the data collection. For the first case study (back pain), an Internet survey was applied, which had advantages in terms of cost, speed of data collection, and access to particular groups. The survey needed to be self-explanatory as there were no interviewers to explain questions and no control for the completeness of the survey (Robson, 2016: p255-256). Specifically, the Internet survey was used to gather insight into healthcare professionals' experiences of diagnosing and delivering back pain treatment and assisted in recruiting some physiotherapists for further in-depth interviews. Besides the benefits mentioned above, it was also convenient to disseminate the Internet survey to healthcare professionals since the survey link could be advertised in the Trust Community Service Cascade (Internal bulletin board).

For the second case study (COPD), a face-to-face survey and a self-completion survey were used. The face-to-face survey was mainly used to measure patients' capability since most people with COPD are older people who most likely need help understanding the questions. In addition, most the questions in this face-to-face survey required Yes or NO answers, which was easier for patients. The self-completion survey was utilised to collect healthcare professionals' feedback in terms of the evaluation of the inclusive service approach and recommendations for service improvements. The main reason for adopting a self-completion survey was to encourage healthcare professionals to comment and be open and critical with the researcher present.

3.4.4 Interviews

The interview is a flexible and adaptable way of finding out people's views. In this research, semi-structured interviews were used in both case studies, since they are more reliable and flexible due to the use of a prepared interview guide and the flexibility on the part of the researcher to modify the interview questions to adapt to the context or situation (Robson, 2016: p285). In terms of the format of the interviews, for the first case study (back pain), both telephone-based and face-to-face interviews were used in order to involve more physiotherapists since they often have high clinical workload and limited availability; for the second case study (COPD), face-to-face interviews were conducted with healthcare professionals and patients, since they involved more interaction, modifications could be made during the enquiry process, and the interview could last up to an hour.

However, Robson also points out the disadvantages of interviews, i.e., it takes time to set up, tape, and transcribe the interviews, as well as to analyse the data (Robson, 2016:p287). An alternative method could be the use of a focus group, which enables the collection of different people's opinions at the same time and participants inspire each other to answer the questions. However, it is quite difficult to make sure everyone expresses their opinions in a focus group since some people may fear speaking in public. In contrast, one-to-one interviews encourage and inspire each individual to share their personal healthcare experience. In addition, interviews are associated with the measurement of patients' individual capability. Therefore, focus groups are not appropriate for collecting data on detailed individual experience. Instead, they were used in the evaluation process of this research.

3.4.5 Focus group

A focus group is an open-ended group discussion on a specific topic which is where the 'focus' comes from, and it is usually guided by one researcher and takes about one hour, possibly two or more (Robson, 2016: p300). A focus group can be used in different stages of the research, such as the preparation of the main data collection and in the evaluation of the research. Regarding this research, a focus group was used to evaluate the findings of the research in the second case study (COPD, in Chapter 6). Conducting the focus group with healthcare professionals and patients was challenging especially, in terms of the ethics and confidentiality, as well as in finding an appropriate venue. Despite these challenges, a local *Breathe Easy support group* made it possible to carry out the focus group. The *Breathe Easy support group*, launched by the *British Lung Foundation*, is a local group for people with COPD who gather

together to support each other, and physiotherapists join in as well. More importantly, most group members welcome researchers to present their research and they are willing to be involved in research. The details of planning, conducting and analysing the focus group are presented in Chapter 5.

3.4.6 Alternative methods

Several alternative methods were considered but not employed in the research, and the reasons are explained below.

Ethnographic study is an alternative method that can be used to collect practical evidence to answer research questions, as it "provides a description and interpretation of the culture and social structure of a social group" (Robson, 2016: p156). However, classically, this type of study requires time, often extending over years to gain an intimate understanding of the group, which was unrealistic in this PhD project. Moreover, the ethics of conducting ethnography in the healthcare area are very complicated, e.g., it is difficult to obtain the permission of all the people within the group since some related people like carers may inevitably be involved. Similarly, another alternative research method, observation, was not appropriate due to the difficulty in obtaining consent from all the people involved in the healthcare system during the observation process.

The use of diaries is an additional alternative method for collecting data on patients' experiences of accessing healthcare services. The main merits of diaries are: i) participants usually feel comfortable with writing a diary and thus some personal and potentially sensitive thoughts are likely to be shared; ii) some temporal sequence of activities, thoughts or feelings can be recorded in a timely manner. However, it is difficult to ensure the completion of diaries, even with participants who are initially enthusiastic (Sim and Wright, 2002: p79). In addition, considering that some people with COPD have declined capabilities and may have difficulties in their daily lives, it is unlikely that they would be able to write a diary every day. Therefore, this method was not used.

3.5 The selection of case studies

Three questions need to be clarified regarding the use of case studies to gather evidence in answering research questions: i) why use the case study method? ii) what are the criteria for choosing cases to study? iii) how can the case studies be carried out? .

3.5.1 Why use the case study method?

Case studies can be viewed as small-scale research with meaning, which can help to deal with very complex issues and be highly influential (Tight, 2017: p59). As mentioned in Section 3.2, the care pathways of community-based care services vary in different conditions and even the in the same circumstances, and patients' journeys may vary as well, so it is challenging to cover all possible pathways. In this regard, a case study is a more feasible and accessible way of understanding community-based care services and patients' care journeys.

Moreover, case studies are widely used in healthcare research. A general characteristic of case study research in healthcare is the focus on using the research to improve people's lives (Tight, 2017: p75), which is also the internal aim of this research. Specifically, the purpose of applying Inclusive Design to healthcare services is to maximise the number of patients accessing healthcare services and thus enable people to manage or curb their conditions and live better. Therefore, the characteristic of the case study in healthcare also coincides with the ultimate purpose of this research.

A case study also utilises multiple methods and tools for data collection and data analysis, which may be used to establish the approach (framework) for other research (Tight, 2017: p96). In this research, two case studies concerning community-based rehabilitation for back pain and COPD were conducted to investigate the application of Inclusive Design to healthcare services. The way in which the first case study (back pain) was carried out provided guidance for the implementation of the second case study (COPD), and the second case study using the same procedures as the first case study could also validate and refine the approach. The approach established in these two case studies could potentially be applied to other healthcare services, particularly community-based treatments of other long-term conditions. This is consistent with the transferability and proven utility of Inclusive Design across many products and services' domains. In addition, it is necessary to be aware of the challenges such as the research resources and time for the generalisation of Inclusive Design across all healthcare services. As a consequence, the research is more focused on generalisation of the process that is used in the case studies.

3.5.2 What are the criteria for choosing cases to study?

Representativeness is one of the main reasons for choosing a case to study, as Thomas (2011: p117) states, 'you may choose it because it provides a particularly good example of something'. In terms of this research, as discussed in Section 2.3.1, community-based care services are the

recommended choices for people living with chronic conditions, so the possible cases are care services for managing long-term conditions. Two points need to be specified in order to further narrow down and define the research scope: *which conditions* and *what related services exist for that condition*. Back pain was selected as the first case study since back pain is one of the most common conditions and almost everyone suffers from back pain at some point in their lives. COPD was selected as a second case study because there is relatively limited research on that condition compared with diabetes and hypertension. More importantly, rehabilitation is a preferred choice for both people with back pain and COPD. Back pain could be managed by people themselves with proper advice and timely treatment but not many people know or take advantage of the community-based telephone assessment service for back pain. Similarly, the uptake and attendance rate for pulmonary rehabilitation, which is recommended for people with COPD to control their conditions, is very low (Royal College of Physicians, 2016).

Another important factor for selecting a case is its feasibility. Firstly, both a community-based telephone assessment service for back pain and a pulmonary rehabilitation service for COPD are available in Cambridgeshire and Peterborough, which means it was possible to collect data locally for this PhD research. Convenience for sampling is important due to the limited time for PhD research. Secondly, collaboration between the related healthcare services providers and research organisations has been built. The Cambridgeshire Community Services NHS Trust and the Centre for Self-Management Support of Cambridge University Hospital were willing to support the first case study related to back pain and the second case study related to COPD, respectively. The results of second case study will be fed into a Research for Patient Benefit project on increasing the referral and uptake of PR. Thirdly, the ethical approval for both case studies was obtained and the details are described in Section 3.6.

3.5.3 How can the case studies be carried out?

Both case studies were mainly based on the collection of data locally: from HCPs in Cambridgeshire and Peterborough and from HCPs and patients in Cambridgeshire. Although the data may seem limited from a geographical perspective, it is pragmatic in terms of availability and variation of healthcare services. The detailed answers regarding how to conduct case studies in terms of sampling, recruiting and characterisation of sample are explained in Chapter 4 and Chapter 5, outlining the specifics of each case.

3.6 Ethics

Research ethics refer to "the moral principles and actions guiding and shaping research from its inception through to completion, the dissemination of findings and the archiving, future use, sharing and linking of data" (Economic Social Research Council, no date). Almost all research that involves human beings requires the consideration of ethical issues. In healthcare research, ethical issues are emphasised since patients could be particularly vulnerable due to their condition or disability (Sim and Wright, 2002). Sim and Wright (2002, p40-41) summarise the central issues in research ethics, i.e., informed consent, privacy and confidentiality, anonymity, deception, risk of harm and exploitation. The main purpose of ethical consideration is to ensure research is carried out without harming the rights and dignity of any participants(Israel, 2014).

In terms of this research, formal ethical approval was needed as patients were involved (some included their carers) as well as healthcare professionals. Specifically, the first case study (back pain) was reviewed and approved by the Research Ethics Committee of the Department of Engineering, University of Cambridge (see Appendix B1). Health Research Authority (HRA) approval was not required in this case study, as patients' experiences were collected from healthcare professionals' perspectives and there was no direct contact with any patients. The second case study involved both patients and healthcare professionals, and the participants were recruited from different research sites (one NHS Foundation Trust, one service provider company, two GP practices), and therefore, Health Research Authority (HRA) approval and a letter of access for research were compulsory. The second case study was ethically reviewed and approved by the Cambridge Central Research Ethics Committee and the study's Research Ethics Committee (REC) reference number is 17/EE/0136 (see Appendix C1). After obtaining HRA approval, confirmation of capacity and capability of the research sites were received by email in order to conduct the study at the properties of these organisations. The letter of access to Cambridgeshire and Peterborough was obtained and research agreements were signed with each GP practice and service provider. Their approval provided the right to recruit participants and conduct questionnaires as well as interviews at these sites.

A *participant information sheet* was provided to each participant to inform them of the research, data collection, and their rights, i.e., they could withdraw their participation at any point and all data was kept anonymous. The consent form was signed before their participation. More details about ethical considerations are introduced in the case studies (Chapter 4 and Chapter 5).

3.7 Summary

The chapter summarises the research paradigm, questions, methodology, and data collection methods and sources that were employed in this research. Specifically, the overall research paradigm adopted here is *realism* which uses a pragmatic, scientific approach for real-world problem-based research. Research questions were reviewed to provide clues for choosing an appropriate research methodology. The DRM framework was used to provide an overall guide for the whole research, while some flexible adjustments and research tools were drawn from the Double Diamond model and the Design Wheel model. Based on the research methodology framework, different research methods were utilised to provide evidence for answering the research question.

4 Case Study 1: Applying Inclusive Design in Improving People's Access to Treatment for Back Pain

This chapter describes the application of Inclusive Design methods to a telephone "Physio-Direct" service for patients with back pain. Mixed methods (online surveys and interviews with healthcare professionals, and collecting patients' personal online care stories) were used to gather insight into the delivery of back pain care and to construct a task analysis of the patient care journey. Task analysis was used to estimate the service demand made on patients' capabilities. Finally, an Exclusion Calculator was used to estimate the proportion of a population that might be excluded from the service as a result of these demands.

4.1 Overview

Case study 1 aimed to investigate how Inclusive Design could be applied to a community-based back pain care service (Liu *et al*., 2018).

Almost everyone is likely to have back pain problems at some point during their lifetime. Back pain is the most common reason for medical consultations and costs worldwide. For instance, approximately 80% of Americans have experienced back pain in their lives and the total costs for the condition have been estimated to be greater than $100 billion annually (Freburger *et al*., 2009); in the United Kingdom, 2.5 million people suffered from back pain in 2006 (Schultz and Gatchel, 2006), and treating back pain cost the National Healthcare Service (NHS) around £480 million per year (McClean, Brilleman and Wye, 2015). Back pain also interferes with people's quality of life and work performance. According to the UK Office for National Statistics, nearly 5 million working days were lost each year due to back problems (Office for National Statistics, 2017c). In addition, back pain patients may also suffer from disability. In 2013, low back pain was the largest single cause of loss of disability adjusted life years, and the largest single cause of years lived with disability in England (Murray *et al*., 2013). Similarly, in 2014, low back pain ranked highest in terms of disability and sixth in terms of overall burden in the United States (Hoy and March *et al*., 2014). Prevalence and burden increase with age. A lack of understanding about back pain (Lustick, 2002) and difficulties accessing treatment are exacerbating the problem.

In fact, in many cases, back pain, particularly lower back pain, can potentially be managed by

people themselves with better information and more active engagement in self-care (May, 2010) rather than through medication and surgery (Yuhas, 2017). The latest BBC news claims that NHS England has decided to stop 'ineffective treatments' and the physiotherapy included as an alternative treatment (BBC News, 2018). In this research, one of the community-based back pain services, the "Physio-Direct" service in Cambridgeshire (a county in the UK) is taken as an example to explore how Inclusive Design might be used to improve healthcare services.

Specifically, there are three main ways that patients can receive back pain treatments in Cambridgeshire: self-referral, the "Physio-Direct" service and General Practitioner (GP) visits. The "Physio-Direct" service is a physiotherapist supported self-management service. Patients with back pain can make a telephone call to a physiotherapist for assessment and advice and be sent with information on self-management or referred to other appropriate services (Taylor *et al*., 2002). This service aims to offer timely assessment and treatment, thus avoiding long waiting times and preventing patients' back pain from worsening in the early stages. It is likely to be more cost effective than usual pathways of care provided by a health service since low-risk patients could self-manage their pain with earlier advice and would not often require further intervention (Salisbury *et al*., 2013). However, self-referral by patients to telephone assessment is limited and most referrals still come from GPs, which means many patients who could use the service may not be aware of it. Moreover, those who were aware of the service may not be able to make the best use of it (Foster *et al*., 2011). Therefore, it is necessary to increase the number of patients using the "Physio-Direct" service to facilitate self-management and reduce the number of patients visiting GPs and hospitals.

4.2 Research design

Case study 1 (CS1) was designed to answer the research questions (RQs), which were summarised in Figure 3.4 of Section 3.2, namely:

- CS1-RQ1 (step 1 - map care journey): What are the care journeys of people with back pain?
- CS1-RQ2 (step 2 - estimate exclusion): To what extent do people's capabilities affect their access to back pain care services?
- CS1-RQ3 (step 3 - identify challenges): How can we use the principle of Inclusive Design to improve people's access along their back pain care journeys?
- CS1-RQ4 (step 4 - propose recommendation): Is Inclusive Design useful to improve the healthcare experience of people with back pain in the community?

These four questions were associated with four steps of the research, and each step addressed one research question. As illustrated in Figure 4.1, an online survey, semi-structured interviews with physiotherapists and secondary data collection of patients' experiences were used in step 1(map care journey). Step 2 (estimate exclusion) and step 3 (identify challenges)involved data analysis: i) task analysis (Stanton *et al*., 2005, Goodman-Deane *et al*., 2014) was used to understand the demands that the service places on patients, ii) an Inclusive Design Tool was used to estimate the proportion of the population who might be excluded from using the service, and iii) challenges of self-managing back pain were identified through the estimation of the care journey's demands on patients, and the online survey as well as interview data. Brainstorming and further interviews were used in step 4 (propose recommendation).

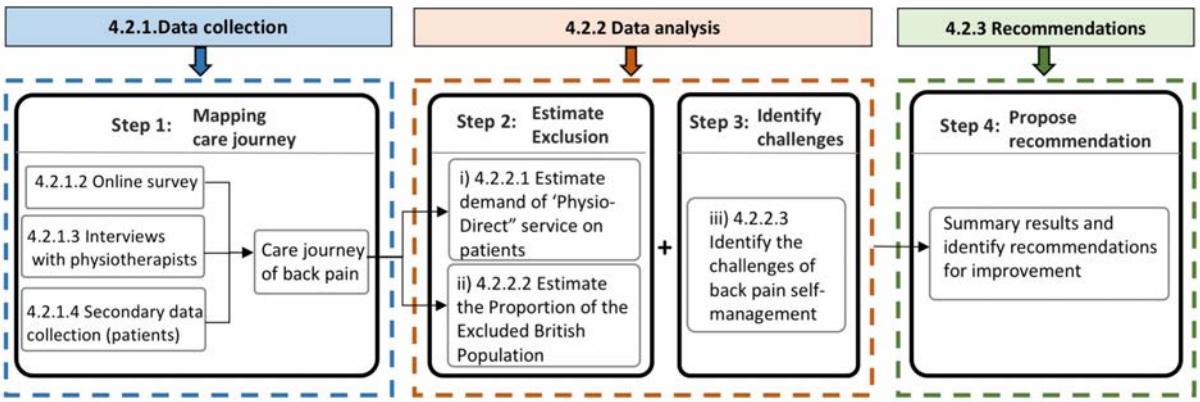


Figure 4.1 Study design (back pain)

4.2.1 Data collection (step 1)

4.2.1.1 Introduction and clarification

In order to map patients' care journey of the "Physio-Direct" service, physiotherapists were recruited and participated in this research by completing an online survey and being interviewed. Secondary data such as patients' online stories and grey literature was collected to complement patients' experience. The details are shown in Sections 4.2.1.2 to 4.2.1.4.

There are two reasons why this case study primarily used first-hand data from physiotherapists and healthcare professionals' perceptions of service delivery to evaluate the heuristic nature of the potential demands and challenges of the "Physio-Direct" service related to patients. Firstly, it takes time (typically up to 1 year) to obtain HRA approval and due to the limitation of time and research ethics, patients were not consulted as part of this case study, and only case study 2 involved patients directly. In an ideal situation, patients would have been involved directly in order to ascertain their experience of accessing the 'Physio Direct' service. Subsequently, i) physiotherapists' views of patients' experience and needs regarding access to the 'Physio

Direct' service were collected; and ii) physiotherapists' own experiences of delivering treatment were also investigated to gain insight into the potential needs of patients. Secondly, it was also useful to explore the possibility of understanding the services' demand on patients' capabilities and identify the potential needs of patients from healthcare professionals' perspectives.

4.2.1.2 Online survey

The survey aimed to gather insight into physiotherapists' experiences and views of delivering back pain treatment, and to assist in recruiting some physiotherapists for further interviews. The detailed design, sampling strategy and results of online survey are presented below:

- **Design**

The online survey (see survey in Appendix B2) was developed from literature review findings (Foster *et al*. 2011; Wright, 2013; NICE, 2016). It included four parts: self-referral; telephone assessment; GP services; and other questions. Two physiotherapists and a senior research fellow from Cambridgeshire Community Services NHS were invited to participate in the design of the survey. For example, for question 10 (Q10), the listed activities that physiotherapists are likely to do during the telephone assessment were suggested by the senior physiotherapist to inspire participants to recall their experiences. Although the pre-defined list could have inhibited participants from expanding on it and adding activities, the answers were complemented by the responses during the later interviews. For ease of completion, most items were closed questions with some open questions requesting more details; the questions could be filled in 5 minutes.

- **Sampling strategy**

The online survey (Qualtrics survey) link was disseminated to physiotherapist leads and advertised in the Cambridgeshire Community Services NHS Trust's Cascade (i.e., a network that spreads news within the Trust Community Service), as the research focused in "Physio-Direct" service in Cambridgeshire area. It was also disseminated by sending the invitation through LinkedIn (i.e., a professional social media network) and email to get more responses. The survey was time limited and had to be returned within two weeks. A further reminder was circulated after the first week.

- **Results**

In total, 33 physiotherapists responded to the online survey. Three responses were invalid since they had no experiences of telephone consultation with back pain patients. Among the other 30 respondents: 77% of the respondents had over five years' work experience in back pain

services, and 57% had been directly involved in telephone assessments. Based on answers to Q10 of the questionnaire, a typical care pathway that physiotherapists may follow during a telephone assessment was identified: i.e., answer the phone; introduce yourself; ask patients' symptoms; measure patients' risk level; request information from other healthcare professionals (e.g., medication review with GP); provide oral advice; send exercise leaflet; and written advice in the post, refer patients to other services such as a visit to the GP and specialists (see Figure 4.2).

Figure 4.2 Care pathway of telephone assessment

This summarised care pathway requires clarification of two points. Firstly, the order of the steps could differ depending on a patient's condition and a physiotherapist's approach, e.g., after enquiring about a patient's symptoms, a physiotherapist may refer the patient directly to hospital if his or her condition has worsened. As a result, the other steps may not apply to this patient. Secondly, the care pathway summarised in Figure 4.2 represents a likely care pathway but does not cover all possible scenarios.

According to the answers to question 12 (Q12) and question 13 (Q13), from the physiotherapists' views, barriers for those patients accessing the "Physio-Direct" service experience were: they do not know the availability of the service, are not sure how to describe their symptoms to physiotherapists and cannot understand the instructions given to them. In addition, from the physiotherapists' perspectives, the main potential challenges were difficulties in building rapport, hearing patients and understanding patients.

4.2.1.3 Interviews with physiotherapists

Semi-structured interviews with physiotherapists were used to further understand their perceptions and experiences of patients' care journeys in self-managing back pain treatment. The detailed design, sampling strategy and results of interviews are described below:

- **Design**

Participating physiotherapists were asked to describe in detail the telephone assessment procedures and share a recent telephone assessment story. Physiotherapists' views about the barriers that prevent patients from accessing telephone assessment and challenges of physiotherapists themselves in delivering assessment were questioned. In particular, the

connection between patients' capability and their access to telephone assessment was investigated based on the physiotherapists' experience (see details in Appendix B3).

- **Sampling strategy**

Convenience sampling of physiotherapists with experience or knowledge of delivering telephone services for back pain in Cambridgeshire was used for this study. The participants were opted in by expressing interest in being interviewed.

- **Results**

Four physiotherapists were interviewed: two face-to-face and two by telephone. Each interview took about 30 minutes and was audio-recorded as well as transcribed verbatim. Patients' detailed care journeys that accessing the "Physio-Direct" service were described from the physiotherapists' point of view. For example, the number of days it normally takes before patients can receive the exercise leaflet and written advice was confirmed with physiotherapists. This detailed information was useful when estimating the service's demand on patients' capabilities (see Section 4.2.2.1).

Besides the communication challenge (i.e., patients were not sure how to describe their symptoms to physiotherapists) that respondents mentioned in the online survey, patients' reduced capabilities, their misconception regarding the service, and the difficulty for them to obtain the correct information regarding self-referral were discussed during the interviews. Some suggestions were also proposed by the interviewees. One physiotherapist said, "sending booklets that have pictures would describe things better (to patients)." Two interviewees mentioned using video calls (skype) could help describe the symptoms and see patients' facial expressions. The importance of patients' direct contact with the service and not via their GP was emphasised by a senior physiotherapist. The detailed results are further discussed in 4.2.3.

4.2.1.4 Secondary data collection (patients)

In contrast to contacting patients directly, the research tried to understand the barriers that prevent patients from accessing the service from the physiotherapists' perspectives. Secondary data complemented patient's experience of receiving back pain care and helped map a patient's care journey. The detailed design and sampling strategy, and results are described below:

- **Design and sampling strategy**

Patients' personal care stories were collected from back pain support groups on social networks such as Facebook and Twitter, and from grey literature within the UK. Keywords: *back pain, "Physio-Direct", telephone (assessment), self-management, self-care, physiotherapist(s),*

GP(s), and *treatment* were the searched. Only the data that matched the study scope, i.e., "Physio-Direct" service for back pain, and described patients' experiences that could help specify patients' care journey were selected.

- **Results**

Few patients' stories mentioned telephone assessment directly, only two patients shared their stories on Facebook and one patient shared their story on the 'Fit for work' blog. As a consequence, the data was not sufficient for coding and further analysis. However, some details of the patients' stories were helpful to understand and specify a typical patient's care journey. For example, one patient wrote, "it takes about 25 mins for me to get connected (with physiotherapists) and - would be better if I could know estimated waiting time". This indicated that patients may experience a long waiting time and the frustration of not knowing how long they must wait.

4.2.1.5 Answering research question (CS1-RQ1)

The purpose of data collection (Section 4.2.1) was to gain insight to answer the research question, *what are the care journeys of people with back pain (CS1-RQ1)*. Based on data from the online survey and interview, as well as the secondary data collection, the potential care journeys that patients are most likely to experience from physiotherapists' perspectives were summarised in Figure 4.3. Since the main target of encouraging patients to use the "Physio-Direct" service is to assist them in self-managing their back pain and thus reduce the GP and hospitals' workload, a recommended patient journey involves receiving verbal advice and a letter to manage their back pain by themselves. It is worth noting that the patients' care journeys listed below do not cover all the possible scenarios for two reasons: i) the data collection did not involve patients directly and the secondary data relating to patients was limited; ii) patients' care journeys were various since different patients exhibited different behaviours and needs.

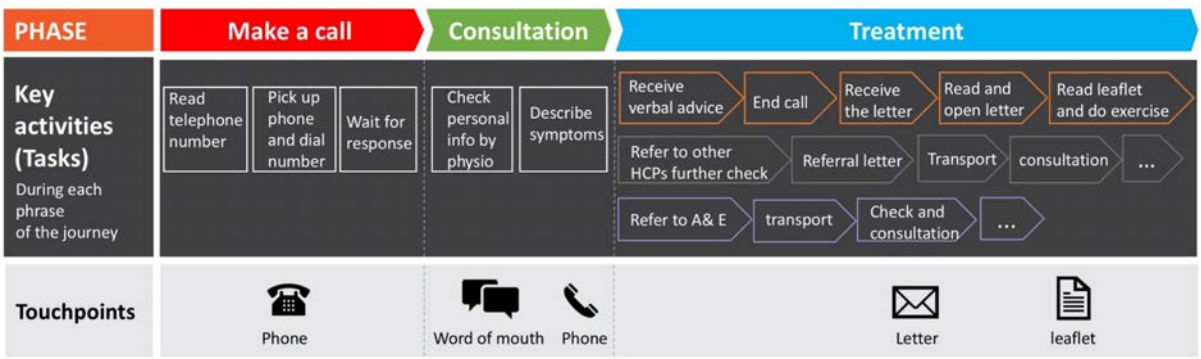


Figure 4.3 Patients' journeys of the "Physio-Direct" service from physiotherapists' perspectives

With regard to the effectiveness of the collected data in answering the research question, understanding patients' care journeys through physiotherapists' experiences could be useful if it is not possible to involve patients directly. It is still very important to utilise other information channels such as patients' support groups and online forums to gather more patients' experiences, which can help understand patients' needs along their care journeys.

4.2.2 Data analysis (step 2 and step 3)

4.2.2.1 Estimate demand of 'Physio-Direct" service on patients (step 2)

It was important to define the scope and analyse a representative patient journey relating to the assessment of the "Physio-Direct" service, as different patients may experience different tasks along their journeys and it was impossible to cover all possibilities. Jerry's story (see Table 4.1) about assessing telephone assessment was developed based on a patient's story from the *Chronic Back Pain Support Group* on Facebook; data collected in the survey and interviews complemented this scenario.

Table 4.1 Jerry: the patient story

Service name	"Physio-Direct" service in the city of Cambridge
User goal being assessed	The service's demand on user's capability when user makes a telephone call, performs a telephone assessment, and does exercise to self-manage back pain.
User scenario	Jerry, 25 years old, works in a laboratory. The lab work forced him to sit or stand for 3-4 hours without rest. One day, he woke up with a very stiff back. Things did not improve after two weeks, so he had to ask for leave. His friend told him there is a "Physio-Direct service available from 1-5 pm on weekdays. Jerry telephoned the service and waited for a response for about 25 minutes, which made his neck stiff. The physiotherapist answered the call and checked Jerry's personal information. He was not sure how to describe his symptoms. He was worried that his pain would affect his work as he could not find a way to get comfortable, either standing or sitting. During the call, the physiotherapist gave him some immediate advice and told him the exercise leaflets would be sent after the call. Jerry received the letter after 5 days. He opened and read the letter, including a summary of treatment and an exercise leaflet. He read the leaflet and did exercise to self-manage his back pain. He found some of the pictures shown in the leaflet were not easily understandable and he hoped someone could give him a face-to-face instruction.

In addition, typical tasks (activities) that a patient is likely to undertake along the care journey are identified in Figure 4.4. The physiotherapist could offer other care options to the patient, but this work only focused on patients self-managing back pain with written advice and the exercise leaflet for better analysis. Based on each specified task, the demand that the "Physio-Direct" service places on patients' capabilities could be estimated.

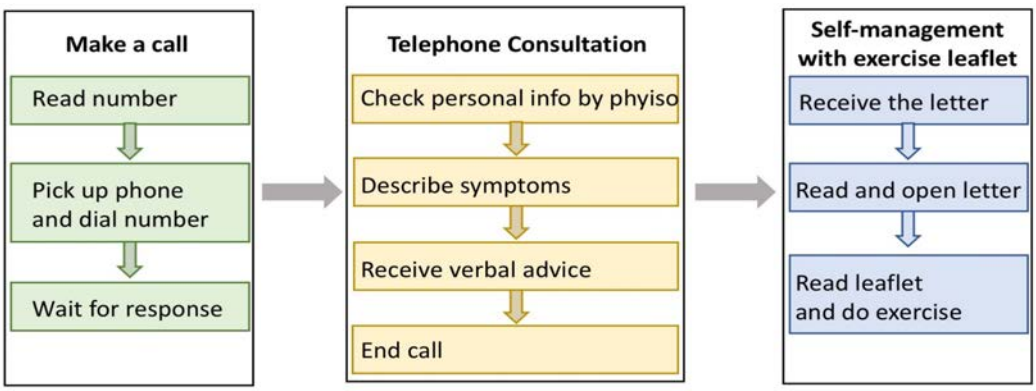


Figure 4.4 A patient's journey of the "Physio-Direct" service

Specifically, the demand of every task was rated by pre-defined scales. These scales were constructed based on the questions in the Disability Follow-up to the Family Resources Survey, which was originally performed to help plan welfare support for disabled people (Semmence *et al*., 1998; Grundy *et al*., 1999; Waller *et al*., 2010; Waller *et al*., 2013). Subsequently, this data has been used to assess numerous products and services. Examples of assessing hearing, reach and literacy demand scales are shown in Figure 4.5 (more detailed scales can be found in Appendix B4). Higher demand on peoples' capabilities causes higher scale ratings, and the symbol ">" (off scale) means it is excessive for a mainstream service.

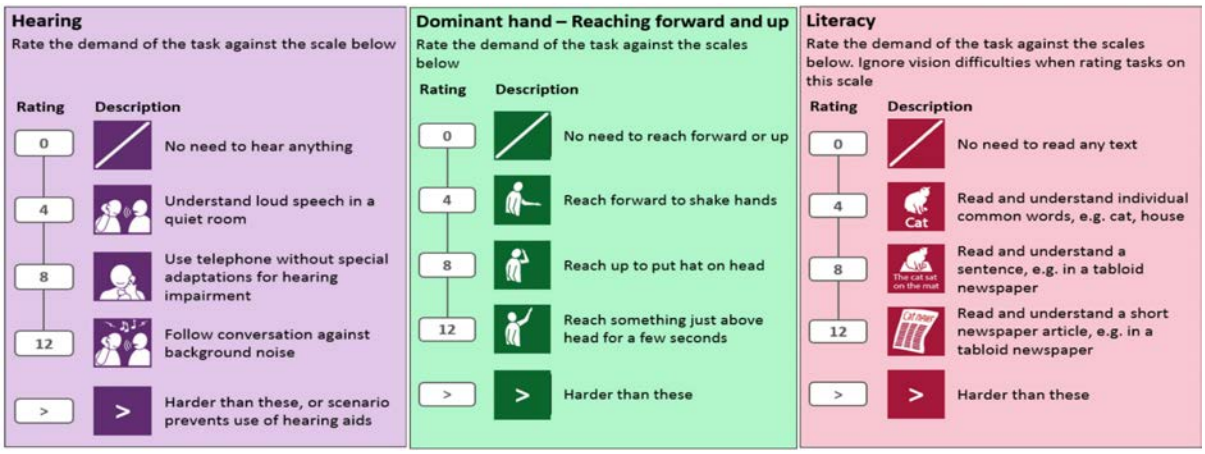


Figure 4.5 The standard of measuring hearing (left), reaching forward and up (middle) and literacy (right). Adapted from http://calc.inclusivedesigntoolkit.com with permission

With the pre-defined scales, the demand on every task was then evaluated. For example, the task "*wait for response*" makes demands on patients' hearing, cognitive ability (concentration, memory and speech comprehension) and motor ability (stretch and forward). The demand of this task on patients' hearing capability is close to '8' on the scale, i.e., "use telephone without special adaptations for hearing impairment" (left picture of Figure 4.5), so it is rated as '8' on the scale; while the demand on patients' reaching forward and up when holding the phone for

25 minutes is harder than '12' on the scale, i.e., "reach something just above head for a few seconds" (middle picture of Figure 4.5), so it is rated ">" off scale. The detailed rating results are listed in Table 4.2.

Table 4.2 Demand on every task of the service (based on Table 1 Jerry's story)

Task No.		1	2	3	4	5	6	7	8	9	10
Task name		Read number	Pick up phone and dial number	wait for response	Check personal info by physio	Describe symptoms	Receive verbal advice	End call	Receive the letter	Read and open letter	Read leaflet and do exercise
	Vision	12	10	0	0	0	0	4	12	12	>
	Hearing	0	0	8	8	8	8	0	0	0	0
	Concentration	12	12	12	12	12	12	12	4	12	>
	Memory	12	12	12	12	12	>	12	4	12	12
	Literacy	4	4	0	0	0	0	0	4	12	>
	Speech Comp.	0	0	4	8	12	12	0	0	0	0
	Speaking	0	0	0	8	12	12	0	0	0	0
	Strength	0	4	4	4	4	4	0	0	0	0
	Dexterity	0	4	0	0	0	12	4	0	0	0
	Forward/Up	0	8	>	8	8	8	6	0	0	12
	Down	0	0	0	0	0	0	4	0	0	12
	Strength	0	0	0	0	0	0	0	1	1	0
	Dexterity	0	0	0	0	0	0	0	6	8	0
	Forward/Up	0	0	0	0	0	0	0	0	4	12
	Down	0	0	0	0	0	0	0	8	0	12
	Walking	0	0	0	0	0	0	0	0	0	2
	Stairs	0	0	0	0	0	0	0	0	0	0
	Standing	0	0	0	0	0	0	0	0	0	8

It is also important to be aware of the uncertainties during the assessment. First, mapping patients' care journeys was influenced by researchers' interpretation about experiences of patients and HCPs. With a better understanding of patients' experience, it would be more possible to map a more representative care journey to be used for assessment. Secondly, there might be discrepancies when different researchers evaluate the demand of tasks, although they follow the same standard of measurements. Therefore, it is useful to have a second analyst and compare the results.

4.2.2.2 Estimate the Proportion of the Excluded British Population (step 2)

In this work, the "*Exclusion Calculator*" was used to estimate the exclusion population based on the rated demand scales of the possible user scenario, i.e., Jerry (Table 4.1 and 4.2). As introduced in Section 2.3.2.3, the "*Exclusion Calculator*" represents a large database of British users with a range of disabilities and quantified information regarding the use of a product

according to their disability (EDC, 2007). The original population data is also from the Disability Follow-up to the Family Resources Survey (Grundy *et al*., 1999), which estimates the proportion of the British population who are unable to use a product or service because of the demands that it places on the users' capabilities. By inputting the estimated demands (rated scale) of each task along the back pain care journey, the "*Exclusion Calculator*" can estimate the number of people within the general population excluded from accessing the "Physio-Direct" service (in every task and on the whole care journey).

Overall, about 15% of British people who experience a similar scenario to Jerry could be excluded from the "Physio-Direct" service. If the back pain was more severe and limiting, then the exclusion would be larger. Among all the service's tasks, it is estimated that the largest percentage of the population is excluded from "*read leaflet and do exercise*" (Table 4.3), namely 13.5%.

Table 4.3 The exclusion of every task

Task name	Read number	Pick up phone and dial number	Wait for response	Check personal Info by physio	Describe symptoms	Receive verbal advice	End call	Receive the letter	Read and open letter	Read leaflet&do exercise	Overall demands
Exclusion (%)	7.2%	8.1%	8.4%	8.0%	8.2%	10.4%	7.2%	10.8%	9.9%	13.5%	15.2%
Vision only (%)	4.1%	2.6%	0.0%	0.0%	0.0%	0.0%	1.0%	4.1%	4.1%	4.1%	4.1%
Hearing only (%)	0.0%	0.0%	2.3%	2.3%	2.3%	2.3%	0.0%	0.0%	0.0%	0.0%	2.3%
Thinking only (%)	4.4%	4.4%	4.5%	4.9%	5.3%	5.3%	4.2%	1.5%	4.6%	4.6%	5.5%
Reach & dex only (%)	0.0%	3.2%	3.9%	2.8%	2.8%	6.2%	3.3%	8.2%	4.8%	9.5%	11.1%
Mobility only (%)	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	6.0%	6.0%

4.2.2.3 Identify the challenges of back pain self-management (step 3)

Challenges of back pain self-management were identified in two ways: i) through the estimation of the care journey's demands on patients; ii) and directly from the online survey and interview data.

According to the Table 4.2, there were five capabilities of three tasks along the patients' care journey rated as ">" off scale (marked in red). The detailed rating reasons are shown in Table 4.4. For example, regarding the task "*receive verbal advice*", patients may not be able to remember all oral advice as they may be offered too much advice or may not be able to understand the advice given. These tasks place excessive demand on patients' capabilities, which implies they are challenges to patients and the patients may need extra support for these tasks.

Table 4.4 The tasks that place high demand on patient's capability

Task name	Wait for response	Receive verbal advice	Read leaflet and do exercise
Capability	Forward	Memory	Vision, Concentraction and Literacy
Reasons rating these challenges ">" off scale	Waiting on hold about 25 minutes to get through the service is challenging.	Patients may not be able to remember all the oral advice.	1. It is difficult for patients to understand some diagrams within the leaflet, e.g. missing movement pictures (Figure4.6, right picture). (Vision & literacy) 2. Patients are not sure whether they do the exercise in a correct way. (concentration)

Framework analysis (Smith and Firth, 2011), which allows data to be themed and categorised, was used to analyse the online survey and interview data (Section 4.2.1.2 and Section 4.2.1.3). The main challenges for patients utilising the "Physio-Direct" service to self-manage their back pain are identified and summarised below (see Table 4.5). Although the amount of interview and online data was limited, it was still possible to identify challenges caused by people's declining capabilities.

Table 4.5 Main challenges for patients using the "Physio-Direct" service from physiotherapists' perspectives

Capability-related challenges	1. Communication	
	Challenges i. Have difficulty describing the nature of the symptom ii. Cannot use body language iii. Cannot describe where their pain is iv. Do not know any anatomy v. Have difficulty understanding doctor	***Interpretation*** i-iii: Patients may feel it is hard to describe the correct area and the nature of their pain. iv-v: Patients are not able to understan some teminologies that physiotherapists use.
	2. Capability	
	Challenges i. Braille copy of exercise required for visually impaired patients ii. Pain when holding the phone over the ear iii. Difficulty hearing as telephone assessment does not allow a third person to help answer iv. Memory and learning difficulties v. Lack of awareness of any disability regarding processing or memory vi. Language barrier	***Interpretation*** i-iii: People with vision and hearing problems may not be able to use telephone assessment. iv-v: The need for memory ability when using "Physio-Direct" service sometimes is neglected. vi: People who cannot speak English may not be able to use the service.
Non-capability-related challenges	3. Perception	
	Challenges i. Are not happy about the telephone assessment option ii. Experience misconception and do not start the treatment iii. Cannot interpret that they can access the service early; Frustrated	***Interpretation*** Patients who have high expectations about the "Physio-Direct" service are likely to feel disappointed as they may be unaware of the service's limitation.
	4. Self-referral to Physio-Direct	
	Challenges i. 80% "self-referral" patients have already seen GP ii. It is hard for patients obtain correct information for self-referral	***Interpretation*** The availablity of "Physio-Direct"service is not well-known.
	5. Relationship between physios and patients	
	Challenges i. Patients not engaging as not wanting to talk over the phone and do not tell GP what exactly they want **ii.** Difficulty in establishing rapport	***Interpretation*** It is more challenging to build rapport with patients over the phone and mutual trust is very important for better care.

The challenges listed in Table 4.5 require clarification, including the capability-related challenges and some non-capability-related challenges (*3. perceptions; 4. self-referral to*

Physio-Direct; 5. relationship between physios and patients). Some of the non-capability-related challenges are in fact linked to people's capability challenges. For example, the patients' perception of the "Physio-Direct" service, not a capability, might affect their thinking capability (e.g., the ability to process information and select appropriate responses and actions). Patients' needs could possibly be interpreted based on non-capability-related challenges, which could be useful in step 4 (propose recommendation).

4.2.2.4 Answering research questions (CS1-RQ2 and CS1-RQ3)

The purpose of the data analysis (Section 4.2.2) was to answer two of the research questions:
i) *To what extent do people's capabilities affect their access to back pain care services (CS1-RQ2)?*
ii) *How can we use the principle of Inclusive Design to improve people's access along their back pain care journey (CS1-RQ3)?*

Specifically, to answer the research question CS1-RQ2 (i.e., *To what extent do people's capabilities affect their access to back pain care services*?), the accessibility of the "Physio-Direct" service was evaluated through task analysis and exclusion calculation. Tasks which placed a higher demand on the patients' capabilities were identified. These included a telephone assessment, waiting for a telephone response, memorising verbal advice, understanding the posted exercise leaflets, and doing the exercises. It was estimated that at least 15% of the British population are potentially excluded from the "Physio-Direct" service. This means the access to the service may be limited when demands on patients exceed their capability, which is a response to the research question CS1-RQ2.

In terms of the research question CS1-RQ3 (i.e., *How can we use the principle of Inclusive Design to improve people's access along their back pain care journey*?), Inclusive Design in this case study was used to understand the "Physio-Direct" service delivery by identifying the service system demand on its patients' capabilities along their care journey. During the mapping of patients' care journeys, barriers that prevent patients from accessing the service were identified. The "Physio-Direct" service's demands on patients' capability were revealed by task analysis and the Inclusive Design tool, Exclusion Calculator. The tasks that placed a higher demand on patients indicate the potential capability-needs of patients and could inspire service providers to improve their services.

4.2.3 Recommendations (step 4)

4.2.3.1 Propose recommendations

Based on the challenges summarised in Table 4.4, brainstorming took place with another two researchers in the EDC, with experience in Inclusive Design and service improvement, to propose recommendations to address the challenges. A further interview and discussion with a Senior Research Fellow from Cambridgeshire Community Services NHS took place to check and refine the recommendations. Specifically, recommendations to address the challenges identified in the estimation of the care journey's demands on patients are proposed in Table 4.6. For example, when patients waiting for physiotherapists answer the call, some general care information can be provided automatically. More importantly, the patient should be informed of the estimated remaining waiting time for the call to be answered. By removing mismatches between the demands made on patients' in their care journeys and their capabilities, the access to service can be improved.

Table 4.6 The recommendations to address the challenges identified from demand estimation

Task name	Wait for response	Receive verbal advice	Read leaflet and do exercise
Challenges	Waiting on hold for about 25 minutes to get through to the service is challenging.	Patients may not be able to remember all oral advice.	1. It is difficult for patients to understand some diagrams within the leaflet, e.g. missing movement pictures (right picture of Figure 4.8). (Vision & literacy) 2. Patients are not sure whether they do the exercise in a correct way. (concentration)
Recommendation	During the waiting period some care information could be provided, minutes counted dow and people reminded to not keep holding the phone.	What can patients do before receiving their written letter? Besides verbal advice, some other options should be provided such as email information or giving a patient information via a website link.	1.The diagrams should better depict the steps of every movement. The instructions of every movement should be given without confusion. 2. Patients may need an assistant (their friends or families) to check whether they do the exercise correctly.

Regarding challenges identified from the online survey and interviews, some recommendations were suggested by the physiotherapists and some were proposed during the brainstorm introduced above (Table 4.7). Some challenges could be addressed by lessen the services' demand on patients' capabilities. However, for challenges that were not relating to patients' capabilities, e.g., difficulty in establishing rapport, which was not belong to Inclusive Design's scope, and might be addressed through training physiotherapists.

Table 4.7 The recommendations to deal with challenges identified from online survey and interview

1. Communication	
Challenges	***Recommendation***
i. Have difficulty describing the nature of the symptom ii. Cannot use body language iii. Cannot describe where their pain is iv. Do not know any anatomy Have difficulty understanding doctor	i-iii: Some visual communication apps such as Skype and Facetime may be used to help patients show their pain areas and to help develp a rapport. iv-v: The physiotherapists should try to use layman's terms to explain to patients.
2. Capability	
Challenges	***Recommendation***
i. Braille copy of exercise required for visually impaired patients ii. Pain when holding the phone over the ear iii. Difficulty hearing as telephone assessment does not allow a third person to help answer iv. Memory and learning difficulties v. Lack of awareness of any disability regarding processing or memory vi. Language barrier	i-iii: A hearing-aid may be needed for patients with hearing problems and for patients with vision problems; it would also be helpful if a person could assist them with the call iv-v: oral advice should be as simple as possible and not offer too many options to patients. vi: Interpreters are required for those patients who do not speak English.
3. Perception	
Challenges	***Recommendation***
i. Are not happy about the telephone assessment option ii. Experience misconception and do not start the treatment iii. Cannot interpret that they can access the service early; Frustrated	It is very important for patients to be aware of the aim and limitation of the service and let the appropriate patients make the best use of the service.
4. Self-referral to Physio-Direct	
Challenges	***Recommendation***
i. 80% "self-referral" patients have already seen GP ii. It is hard for patients obtain correct information for self-referral	The service should be promoted in various channels and let as many people as possilbe know about it.
5. Relationship between physios and patients	
Challenges	***Recommendation***
i. Patients not engaging as not wanting to talk over the phone and do not tell GP what exactly they want ii. Difficulty in establishing rapport	It is very important to train physiotherapists in communicating with patients over the phone.

It was worth noting that some of the challenges may be identified without using an Inclusive Design approach, for example, people dialling into a helpline without a headset may get a stiff neck. However, the Inclusive Design approach could provide a more comprehensive systems approach to look at all the potential challenges along the patients' care journeys rather than at a single point. Also, while some of the recommendations for improvement may have been already used in the private sector of telephone services, e.g., service callers have been informed how long they are to wait, this information has not yet been applied to community healthcare services. Nonetheless, Inclusive Design does provide a systematic and holistic approach to improve healthcare services and thus increase the patients' access.

4.2.3.2 Answering research questions (CS1-RQ4)

The purpose of proposing recommendations to address potential challenges that patients may encounter was to gather more evidence to answer the research question, *Is Inclusive Design useful to improve the healthcare experience of people with back pain in the community* (CS1-RQ4)?

In fact, this question has two aspects in terms of improving the service:
i) *Is Inclusive Design useful to understand and identify patients' need?* The first aspect of this question was partly addressed in Section 4.2.2.4, as it is closely linked with the answers to the research question (CS1-RQ3), which claims that Inclusive Design could signal the needs of patients. A more detailed explanation was given in Section 4.3 (the fourth point).
ii) *Is Inclusive Design useful to address patients' needs and thus improve their healthcare experience?* Inclusive Design appears to be useful to address patients' needs. Recommendations to address patients' needs were proposed (see Table 4.6 and Table 4.7 in Section 4.2.3.1). However, further work is required to validate this answer.

4.2.4 Research bias

To minimise the acquiescence bias, the online survey was designed with physiotherapists and a senior research fellow, and the interview procedures were discussed with a senior researcher at the EDC. To reduce the risk of confirmation bias during data analysis, a second researcher from the EDC rechecked the assessment. The primary and secondary analysts compared results and resolved any discrepancies. Should any differences not have been resolved, the supervisor of this research would have played the role of adjudicator. In addition, the research protocol was reviewed and approved by the Research Ethics Committee of the Department of Engineering, the University of Cambridge, which also helped to reduce the confirmation bias.

4.3 Discussion

It is necessary to revisit the concept of Inclusive Design before discussing how it has been applied in this case study. Inclusive Design refers to ensuring the service demand made on individuals does not exceed their capabilities to respond, and thus a service is accessible to people with the widest range of capabilities. In this case study context, the aim of applying Inclusive Design was to identify the "Physio-Direct" service's demand on patients, understand potential patients' capability-related needs when accessing the service, and thus increase the number of patients using the service to self-manage back pain. Figure 4.6 presents a summary of how the research was carried out in order to investigate the application of Inclusive Design in this case study.

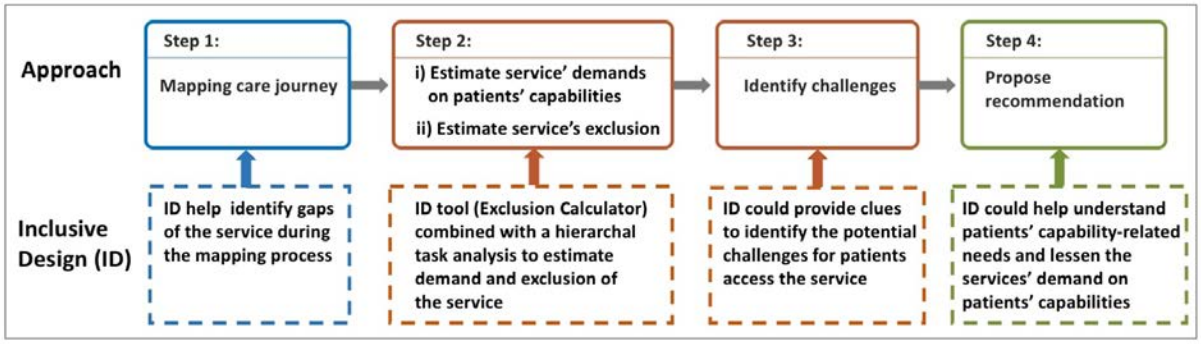


Figure 4.6 A summary of applying Inclusive Design in case study 1

The first step was to understand how patients access the "Physio-Direct" service, i.e., mapping the care journeys of patients and identifying the detailed tasks along the care journeys. This is because the Inclusive Design approach to estimating the service demand on patients' capability requires a clear map of the service delivery and an understanding of the tasks on the users' care journey. Gaps in the healthcare service could possibly be identified during the process of mapping the patients' care journey. For example, it was easy to miss the gaps after the telephone assessment and before patients received written advice, when patients could forget the verbal advice (Figure 4.7). During this waiting period, some other options, such as giving the patient information for a website link or emailing information, could be offered to help patients control their pain. Estimating the demands of every task within the service more rigorously could help to provide a better understanding of patients' needs.

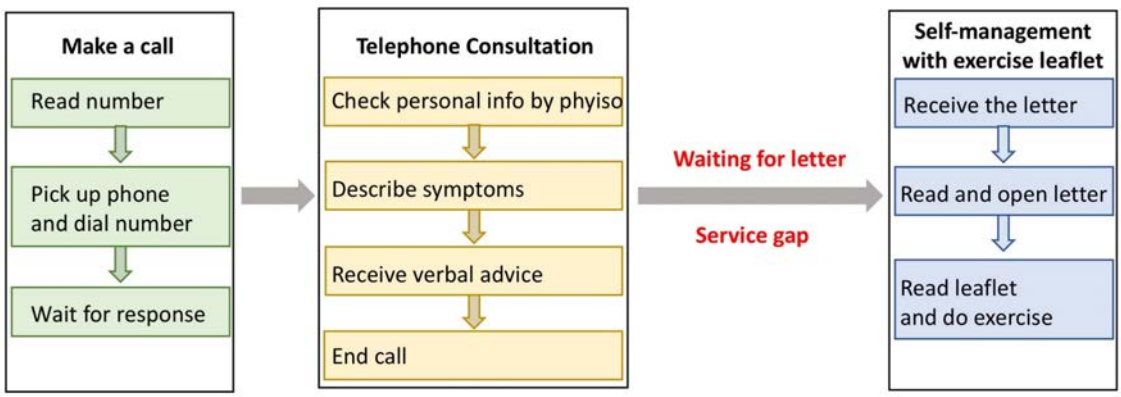


Figure 4.7 Service gap during the period 'waiting for letter'

Secondly, a hierarchal task analysis and the Exclusion Calculator (an Inclusive Design tool) were used to estimate the service's demand on patients and the service's exclusion. Specifically, the demand of each task and the whole care journey could be assessed by the pre-defined scales, which were constructed according to the 1996/97 Disability Follow-up to the Family Recourses Survey (Grundy, *et al*., 1999, see Section 2.4.2.3 for more information). The tasks that place a higher demand on patients' capabilities were identified during the assessment.

Meanwhile, the proportion of the British population potentially excluded could be estimated by the Exclusion Calculator (Inclusive Design tool, see Section 2.4.2.3). In summary, Inclusive Design methods can help identify the service's demand on patients and estimate the service's exclusion.

Thirdly, the most challenging aspects for patients accessing the "Physio-Direct" service were indicated by two sources: i) the rated demand and the excluded number of people; ii) the online survey and interview data. This step evidenced that the rated demand and the excluded number of people estimated by the Inclusive Design tool could provide clues to identify the potential challenges for patients accessing the service.

Fourthly, recommendations were proposed to lessen the service's demand on patients' capabilities and make the service more inclusive. This showed that Inclusive Design could potentially help understand patients' capability-related needs and make the service more inclusive and hence increase uptake. Specifically, when designing a healthcare service, care providers often tend to assume patients can do some "simple" tasks such as make a call and remember medical advice. In fact, some tasks are beyond some patients' capabilities. An example is the task, "*read leaflet and do exercise*", which causes the largest percentage of the population to be excluded from the care journey (Table 4.3). Figure 4.8 shows two movements from the NHS's back pain exercise leaflet. Exercise No. 6 has two sub-pictures with the steps of movement, which are relatively easy for patients to follow, while Exercise No. 7 does not show how to start the movement, so patients could become confused by the picture and not benefit from the exercise. However, if these capability-related needs could be understood when the service is designed, e.g., by making the exercise diagrams clearer, patients would be less likely to be excluded from the service.

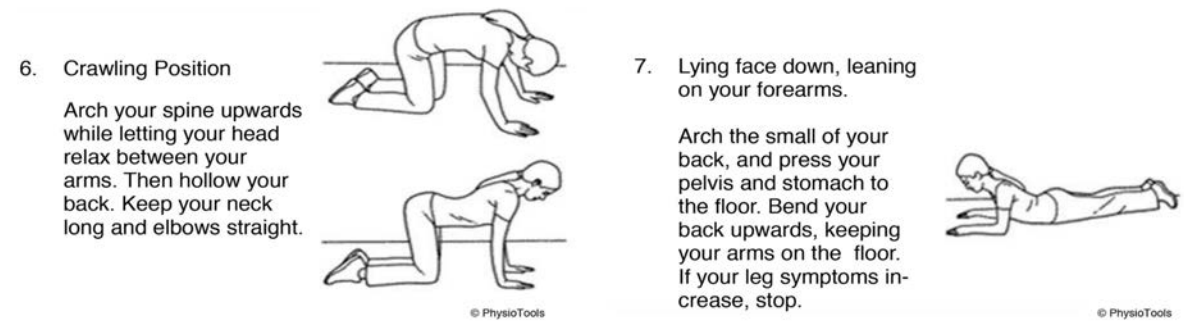


Figure 4.8 Example movements from Low Back Pain Exercise Booklet of NHS.
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4.4 Summary

In this case study, Inclusive Design was used to understand the "Physio-Direct" service delivery by identifying the service system demand on its patients' capabilities along with their care journey. An online survey and interviews were used to help understand the patients' journeys in accessing the "Physio-Direct" service and identify the advantages and limitations of the service. The accessibility of the "Physio-Direct" service was evaluated through task analysis and exclusion calculation. The tasks that place a higher demand on patients' capabilities were identified and the proportion of the British population potentially excluded was estimated.

As for the limitations of conducting this case study, the number of interviewees was relatively low because of the difficulty in recruiting physiotherapists due to their high clinical workload and limited availability. Although this research was more focused on understanding the barriers of patients' back pain self-management from healthcare professionals' points of views, inputting first-hand data directly from patients is equally important. In addition, the population database on people's capabilities used has not been updated for about 20 years, although it remains the most holistic source of data.

Overall, this case study has demonstrated that the application of Inclusive Design to health services is possible and the tools applied can make a useful contribution to understanding service provision and hence service improvement. However, the research procedure was used in only one case study. Whether it could be adapted and applied to other healthcare services and conditions still needs to be further explored. Meanwhile, it is very important to be aware of the scope and limitations of Inclusive Design in healthcare services, i.e., Inclusive Design methods and tools consider physical and cognitive exclusion, while other types of exclusion, i.e., social and psychological, are not included in the analysis.

5 Case Study 2: Applying Inclusive Design in Improving People's Access to Pulmonary Rehabilitation

The previous chapter demonstrated that Inclusive Design could be applied to better understand healthcare service provisions and improve patients' experience of accessing these services.

This chapter further explores the application of Inclusive Design methods to a community-based healthcare service, i.e., pulmonary rehabilitation (PR) for patients with chronic obstructive pulmonary disease (COPD). Mixed methods, including qualitative research (semi-structured interviews) and quantitative analysis, were used to understand patients' care journeys and identify barriers that affect the referral and uptake process of PR, in particular, those barriers caused by not considering the reduced capabilities of patients with COPD. Also, an (inclusive) approach that can help to better understand people's capability demand within the process of PR was proposed and refined with input from patients as well as healthcare professionals (HCPs).

5.1 Overview

Case study 2 aimed to investigate how Inclusive Design could be applied to the community-based PR service for people with COPD in the East of England.

- **Underutilisation of pulmonary rehabilitation (PR)**

COPD is a progressive lung disease in which people experience breathlessness, exercise incapacity and vulnerability to exacerbations, frequently requiring hospitalisation. According to the World Health Organisation's (WHO) estimates, 65 million people have moderate to severe COPD (WHO, 2016). Globally, it is estimated that about three million deaths were caused by the disease in 2015 (that is, 5% of all deaths globally in that year). Approximately 1.2 million people live with COPD (British Lung Foundation, 2012) in the UK and a large proportion of them are older people. This condition costs the UK National Health Service (NHS), a publicly funded national healthcare system, £800 million per year, mostly relating to hospital admissions (NICE, 2011). The UK National Institute for Health and Care Excellence (NICE) recommends that PR, providing supervised exercise and education, can be offered to patients functionally disabled by COPD (NICE, 2016). PR improves symptoms, exercise capacity and quality of life (McCarthy *et al*., 2015) and leads to fewer repeating exacerbations requiring admission or hospital attendance (Seymour *et al*., 2010; Griffiths *et al*., 2000). In contrast to health sciences, which focus on the treatment and management of COPD from the

biology of the disease (The Lancet, 2017), PR focuses on fostering self-management skills for patients themselves (Singh *et al*., 2013).

The National COPD Audit Programme (2016) estimated that the number of COPD patients eligible for PR in England and Wales in 2013/14 was 446,000; however, despite evidence-based guidelines (Bolton *et al*., 2013; NHS Service Specification, 2012) there were only 68,000 referrals (15% of normative need) during that period and only 69% of those attended an initial assessment (10% of normative need) (Royal College of Physicians, 2016). Referral and attendance figures in the East of England are not currently available, but there is no reason to believe that the local figures are significantly different from the national figures. The audit highlighted the need to improve referral and uptake rates. It recommended that PR referral pathways, healthcare professional training, information for patients and referrers and barriers to patient access should be reviewed. The audit also demonstrated that the COPD treatment might not be accessible to people with disabilities (Royal College of Physicians, 2015).

- **The evidence of gaps**

Several studies have been carried out to identify barriers that prevent access to PR (Harris, Hayter and Allender, 2008; Johnston *et al*., 2012a; Barr *et al*., 2005; Yawn and Wollan, 2008; Johnston *et al*., 2012b; Perez *et al*., 2012; Keating *et al*., 2011; Thorpe *et al*., 2012; Mathar *et al*., 2015). Most of these barriers have been identified as relating to the context or environment, people's knowledge, and patients' and clinicians' beliefs (Cox *et al*., 2017). For example, referral to PR can be influenced by a complex referral process and a lack of knowledge about PR, while uptake can be affected by the lack of transport and geographic distance to a program, as well as the quality of the HCP's conversation with patients about PR.

However, there is little understanding of how patients' own capabilities relate to their access to PR and affect implementation of the care service. For patients with COPD, a large proportion are older people (British Lung Foundation, 2012) whose COPD condition, as well as the ageing process, may significantly impact their capability. People with COPD may be more frail, weaker and have reduced exercise and activity levels (Maddocks *et al*., 2016). Moreover, they may be burdened by high levels of anxiety and depression as well as recognised cognitive impairment, particularly at the time of exacerbation (Pierobon *et al*., 2017). Many patients exhibit significant differences in their own functioning compared to their peers. While some of these manifestations relate solely to the presence of COPD, multi-morbidity is common and clearly could further impact patients' capabilities. In addition, people's personal capability to access a healthcare service is a prerequisite for them to use it.

Hence, it is essential to consider patients' capabilities in order to improve access to PR services. Insight into the capability demand within the COPD care pathway (i.e., the demands that the care pathway makes on people's capability) could help care providers to understand the needs of patients better and to support their engagement in PR. Therefore, this case study focused on understanding people's capability-related needs while accessing PR within the community.

- **The aim of the study**

The study aimed to provide recommendations for how primary care PR services in the East of England could improve and increase patients' access to PR services. An Inclusive Design approach was used to estimate the system demands on patients with COPD and evaluate PR services' exclusion, identifying ways in which the care pathway excludes patients and ways in which the care pathway design can be modified to provide inclusive access to PR for as many eligible patients as possible. It is worth noting that most people who go to PR have COPD, but people with other long-term lung conditions, such as bronchiectasis and pulmonary fibrosis, can also benefit from PR. This study only focused on people with COPD accessing PR services.

5.2 Research design

The study procedures, sampling and recruitment, study setting, patient and public involvement, research bias, and ethics and dissemination are discussed below.

5.2.1 Study procedures

Case study 2 (CS2) was designed to answer the four research questions (RQs), which were summarised in Figure 3.4 of Section 3.2, namely:

- CS2-RQ1 (step 1 - mapping pathway): What are the care journeys of people with COPD?
- CS2-RQ2 (step 2 - estimate exclusion): To what extent do people's capabilities affect their access to community-based PR services?
- CS2-RQ3 (step 3 - identify challenges): How can we use the principle of Inclusive Design to improve people's access along their PR journeys?
- CS2-RQ4 (step 4 - propose recommendation): Is Inclusive Design useful to improve the healthcare experience of people with COPD in the community?

These four questions corresponded to the four steps of the research and each step addressed one research question. As illustrated in Figure 5.1, the case study was also divided into four steps. Step 1 (mapping pathway) involved interviews with HCPs and patients to gather insight

into their experiences and produce a hierarchical task analysis (Stanton *et al*., 2005, Goodman-Deane *et al*., 2014) of the COPD care journeys. Step 2 estimated the service exclusion: the demand of every task on patients' capabilities was rated by pre-defined scales and the proportion of the population excluded from the service was estimated by an exclusion calculator. Step 3 identified the challenges of the PR service: a framework analysis (Smith and Firth, 2012) guided further data analysis of the interviews. Step 4 proposed recommendations for a COPD care reminder, which would help patients manage their COPD care, informed by addressing the challenges identified in step 3 and refined through a survey and focus groups.

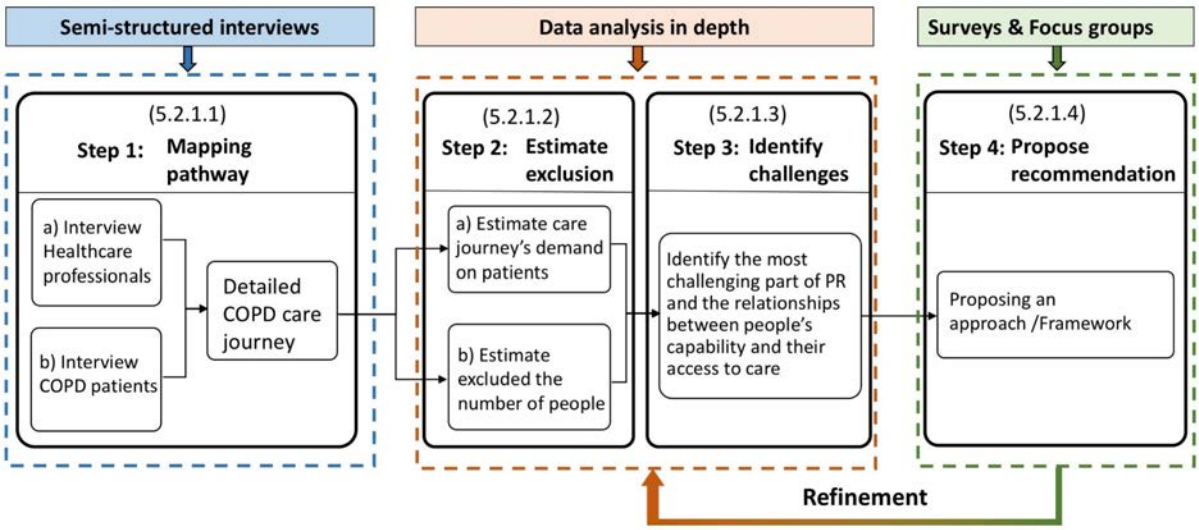


Figure 5.1 Study design (COPD)

5.2.1.1 Step 1: Mapping pathway

In order to map patients' COPD care journey, semi-structured interviews with HCPs and patients were conducted to gather insight into their experiences and perceptions of the COPD care pathway and care journeys respectively. It is important to clarify that this research only identified the COPD care pathway (journey) that related to patients' access to PR services. Patients' ability to do exercises and take part in PR once they accessed the service and the PR programme itself were not the focus of this research (see Figure 5.2). Specifically, step 1 contained 3 parts: a) Interviews with healthcare professionals (HCPs), b) Interviews with patients, and c) Answering research question, i.e., what are the care journeys of people with COPD (CS2-RQ1)?

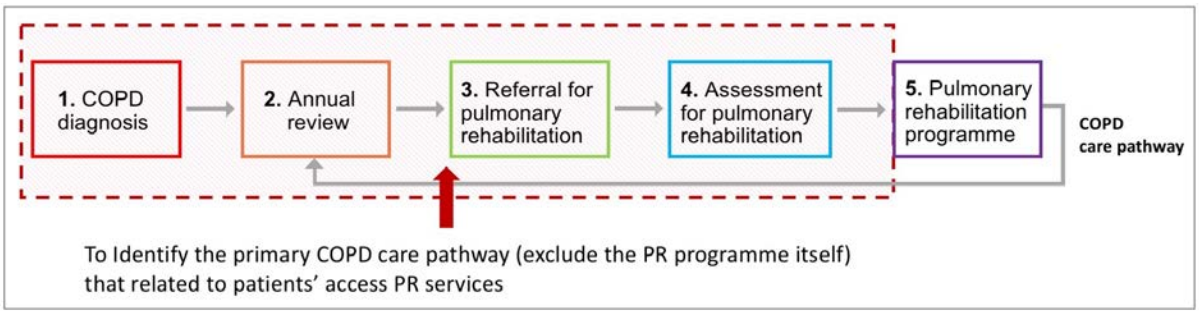


Figure 5.2 The research scope of the care pathway

a) Interviews with healthcare professionals (HCPs):

There were mainly three purposes to the interviews with HCPs:
i) To understand HCPs' experiences and perceptions of the COPD care pathway and thus help map patients' care journey;

ii) To understand the most challenging aspects of patients' accessing PR from the HCPs' perspectives;

iii) To check whether there are any connections between patients' capabilities and their ability to access PR based on the HCPs' experience.

The design, data analysis and results of interviews with HCPs are described below:

Design

An interview schedule was developed and piloted with two researchers of EDC and two patients informally to ensure questions were neutral and useful in answering the research questions, and the interview time was sufficient. Specifically, the initial semi-structured interview schedule (see Appendix C2) was divided into three parts:
i) *Opening* to introduce the research to participants;

ii) *Body* including three topics, i.e., PR pathway of HCPs, HCPs' perceptions and experiences of PR services, the relationship between capabilities and accessibility;

iii) *Closing* to express gratitude and check whether participants had any questions.

The interview schedule and questions were refined and updated following an initial interview with one HCP (see the second version in Appendix C3). An A4 card containing the main stage of the NHS primary care pathway for COPD (see Figure 2.14) was presented to HCPs to gain insight into their perceptions and experience of the COPD care pathway and inspire them to recall their experiences. More importantly, the interview questions were categorised and printed on different A4 size cards based on the different stage of the NHS primary care pathway

for COPD. An example of the stage "referral to PR" is shown in Figure 5.3 and more details can be found in Appendix C3.

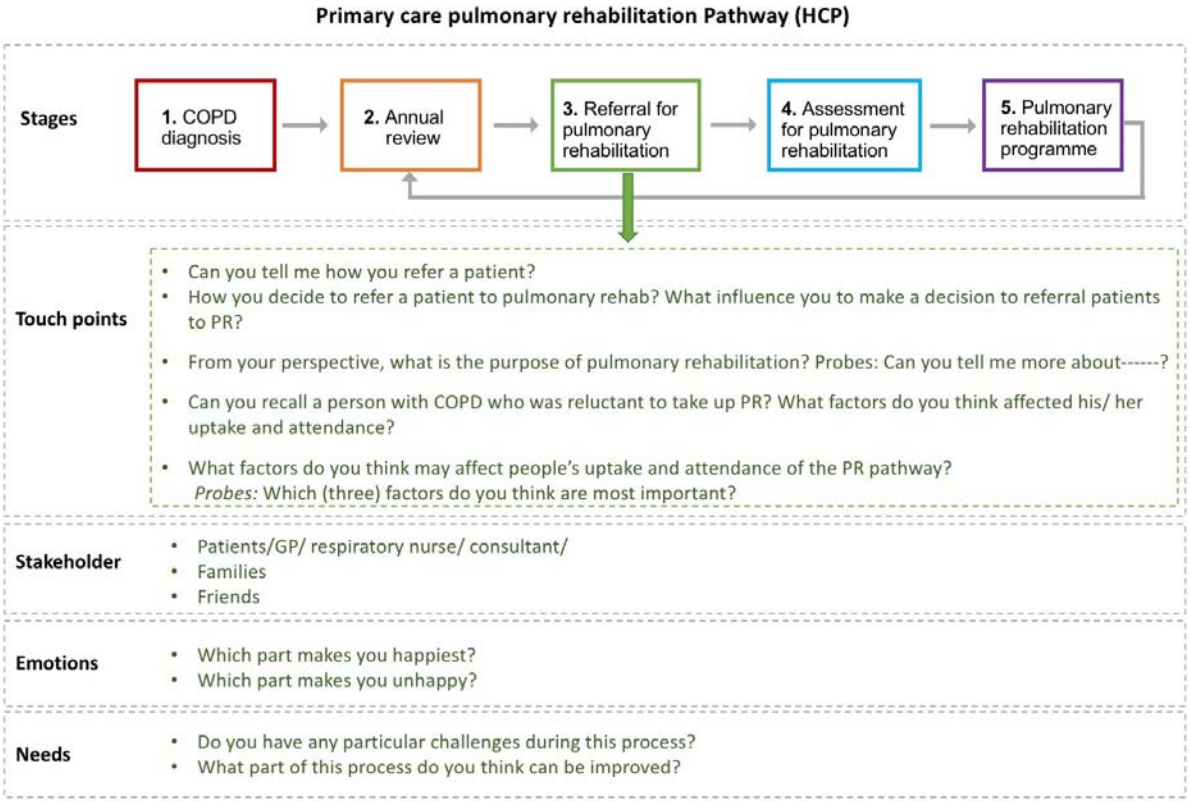


Figure 5.3 An example of the interview card for HCPs (Stage: *referral* for PR)

There were two advantages of this classification. First, since different HCPs were involved in different stages of the care pathway, the interview time could focus specifically on the aspects of their involvement. For example, the GP was mainly responsible for the *diagnosis* and *referral* stage; therefore, the interview could focus more on the interview cards concerning these two stages. Second, data analysis was facilitated by compiling data from all the questions relating to each stage. In addition, the question cards could also be presented to participants to help them understand the questions if there were any issues concerning accents.

Interviews were conducted with HCPs (including GPs, practice nurses, and physiotherapists) who refer patients to PR, as well as PR service managers and healthcare commissioners (details of *sampling and recruitment* are in Section 5.2.2, p124-125). The interview invitations package was sent to the potential participants by email and in person. It contained an invitation letter (see Appendix C4), a lay summary (see Appendix C5) and a participants' information sheet for interviewing HCPs (see Appendix C6). A further reminder email was circulated after one week. The consent form (see Appendix C7) was signed before the interviews.

Data analysis and Results

In total, nine HCPs were involved in interviews. The interview process was audio-recorded and transcribed verbatim. Transcriptions and field notes were managed and analysed using NVivo 12, a software support tool for qualitative and mixed methods research, which is designed to help organise, analyse and find insights in unstructured or qualitative data (Bazeley and Jackson, 2013). The activities that HCPs would do within primary care were coded based on the care pathway's stages (*Diagnosis, Review, Referral, Assessment, and PR programme*) in NVivo.

The representative primary care HCPs' pathways for PR were identified and are summarised below (see Table 5.1). It is worth emphasising four points: i) the focus was on the pathway from diagnosis to PR programme attendance while recognising the number of possible different routes to PR referral; ii) this stage was mainly to use the interview data to map care pathways of HCPs, and further analyse interview data conducted in Section 5.2.1.2; iii) some of the specific tasks under the activity were listed sequentially, for example, in stage *Diagnosis* of table 5.1, the No.2 activity "*Undertake consultation*" can be specified into tasks "*ask patient's symptoms*", "*examine patient chest and breathing*", etc. While some of the specific tasks under the activity are parallel, which means the HCP may just do one of the asks - for instance, the No.3 activity "*Refer to further check*" can be detailed to the task "*refer to secondary care*" or "*refer to the practice nurse/community*", etc; vi) the stage *Annual Review* has been renamed as *Review* since some severely affected patients have their reviews every six months instead of annually.

Table 5.1 HCPs' specific tasks on the care pathway

Stage	**Diagnosis**									
No.	1	2	3	4	5	6	7	8	9	10
Activities	**Have an appointment with patient**	**Undertake Consultation**	**Refer to further check**	**Do Diagnosis test (community)**	**Inform result**	**Educate patients**	**Offer treatment**	**Discuss care plan**	**Refer for further check**	…
Specific tasks	Call patient's name	Ask patient's symptoms	Refer to secondary care	Do spirometry test	Face-to-face	Explain COPD	Inhalers	Stop smoking	Refer to hospital for further check	
	Greetings	Examine patient's chest and breathing	Refer to Practice nurse/ community	Do COPD assessment Test (CAT)	Call	Provide information for reassurance	Pulmonary rehabilitation (PR)	Provide suggestions for self-management	Refer to specialist for further check	
	…	…	…	…	…	…	…	…	…	
Main HCPs	GPs	GPs	GPs	Nurses/ Physios	Nurses/GPs Physios	Nurses/GPs Physios	Nurses/GPs Physios	Nurses/GPs Physios	GPs/ Physios	

Table 5.1 HCPs' specific tasks on the care pathway (continued)

Stage	Review						Referral				
No.	1	2	3	4	5	6	1	2	3	4	5
Activities	**Send invitation to review**	**Undertake health check for COPD patients**	**Review medication**	**Refer patients to PR**	**Check patients' mental health**	...	**know criteria for referral**	**Make a decision for referral**	**Selling PR**	**Fill the referral form**	...
Specific tasks	Send letter to remind patient	Do spirometry test	Check inhaler technique	Selling PR to patients	Talk about psychological health		Check the criteria for referral	Calculate patients' MRC score	Understand patients' needs	Obtain the referral form	
	Call patient to remind	Test oxygen saturation	Offer rescue pack	Provide BLF leaflet to patients	Reassure patients		Seek for information for referral	Check patients' symptoms	Provide patients' PR information	Fill in patients' information	
	...	...	...	...	...		...	...	...	...	
Main HCPs	Nurses	Nurses	Nurses	GPs/Nurses			Nurses/GPs/ Physios	Nurses/GPs/ Physios	Nurses/GPs/ Physios	Nurses/GPs/ Physios	

Stage	Assessment						Pulmonary Rehabilitation (PR)						
No.	1	2	3	4	5	6	1	2	3	4	5	6	7
Activities	**Have an appointment with patient**	**Assessment**	**Make a decision**	**Discussion**	**Inform patients**	**...**	**Prepare before PR session**	**Guide exercise**	**Offer Tea and break**	**Give education lecture**	**Finish PR session**	**Finish the whole PR programme**	**...**
Specific tasks	Call patient's name	Measure patients' blood pressure	Approve patients' attendance	Provide patients' PR information	Inform patients of the date of class		Check patients' attendance	Guide patients to do exercise	Offer tea	Give a talk about COPD care	Confirm patients leaving rehab centre	Send feedback to GPs	
	Greetings	Review patients' medication	Delay patients' attendance	Tailor the class for patients	...		Check patients' status	Tailor the exercise for some patients	Chat with patients	Answer patients' questions	Answer patients' questions	Offer patients advice for self-management	
	...	...	...	...			...	...	...	...	...	...	
Main HCPs	Physios	Physios	Physios	Physios	Physios		Physios	Physios	Physios	Physios	Physios	Physios/GPs	

b) Interviews with patients:

The purposes of involving patients with COPD in the research are listed below:

i) To capture the detailed COPD care journey from patients' perspectives;

ii) To gather insight into patients' experiences of PR and their care needs;

iii) To assess the capabilities of patients with COPD.

The design, data analysis, and results of interviews with patients are presented below:

Design

Similar to the interview schedule with HCPs, the interview schedule for patients was also designed and piloted with two researchers of EDC and two patients informally to ensure questions were neutral and useful to answer the research questions, and the interview time was sufficient. Specifically, the initial semi-structured interview schedule (see Appendix C8) was designed in four parts:

i) *Opening* section to introduce the research to participants;

ii) *Body* including three topics, i.e., COPD journey of people with COPD, needs of people with COPD, and the relationship between capabilities and accessibility (including a capability

measure test, and the detailed questions which can be seen in Appendix C9, were informed by and adjusted according to the Disability Follow-up to the Family Resources Survey);

iii) *Personal information* to know more background about the participants;

vi) *Closing* to express gratitude and check whether participants had any questions.

The interview schedule for patients (Appendix C10) was refined and updated in a similar way to the second version of the interview schedule for HCPs (see the second version in Appendix C3). An A4 card containing the main stage of the NHS primary care pathway for COPD (see Figure 2.14) was presented to patients to check their experiences of the COPD care pathway and gain insight into their detailed care journeys. The interview questions for patients were categorised and printed on different A4 size cards based on the different stage of the NHS primary care pathway for COPD (Figure 5.4).

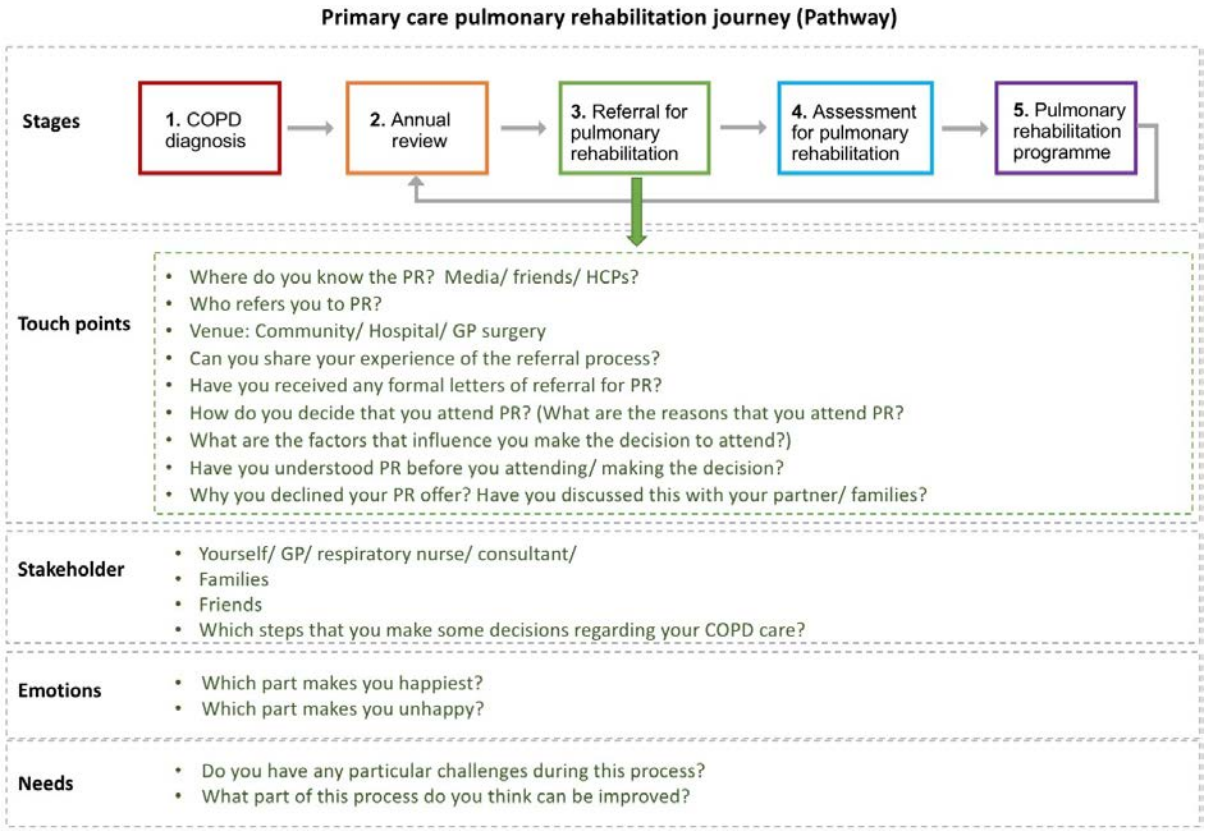


Figure 5.4 An example of the interview cards for patients (Stage: *referral* for PR)

Besides, the interview questions (see the left of Figure 5.5) including questions for the capability measure test (see the right of Figure 5.5) were also printed in a large font size on A5 size cards to present to patients if necessary, to overcome patients' potential hearing impairments or difficulties understanding a different accent.

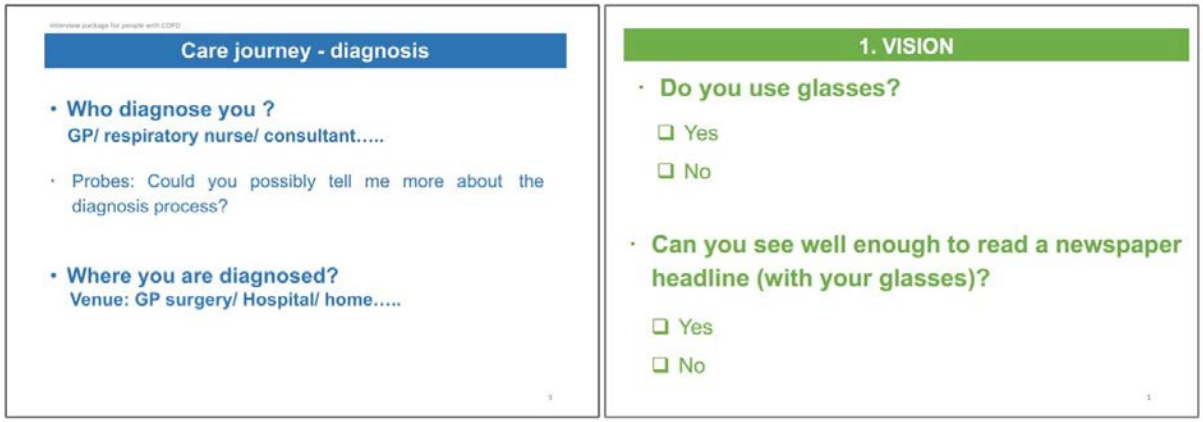


Figure 5.5 A5 interview cards to assist interviewing patients

Three categories of patients with COPD were interviewed: patients who had accepted a PR offer, patients who had declined a PR offer and patients who had never been referred to PR (see section *sampling and recruitment* for details). The interview invitations package was given to the potential participants by their GPs, nurses, physiotherapists or PR providers. It contained an invitation letter (see Appendix C11, C12, and C13), a lay summary (see Appendix C5) and a participants' information sheet for interviewing patients (see Appendix C14). The invitation letters were slightly different depending on patients' category, i.e., accepted PR, declined PR or not referred to PR. Participants who agreed to participate could leave their contact information at the bottom of the invitation letter and give it to HCPs, or they could contact the researcher directly. The consent form (see Appendix C15) was signed before the interviews.

It is necessary to aware of the advantages and disadvantages of recruiting patients through HCPs, which could help to involve patients, especially those difficult access patients (e.g., patients who are not referred to PR or declined PR), into research and also accelerate the recruiting speed, although the participants may be more interested in research.

Data analysis and Results

In total, 16 patients with COPD were involved in interviews: 9 patients who had accepted the PR offer, including two patients who had declined the second PR offer and one patient who had never been referred again, five patients who had not been referred to PR, and two patients who had declined the PR offer.

The interview process with patients was also audio-recorded and transcribed verbatim. Transcriptions and field notes were managed and analysed using NVivo 12 software. The activities that patients would do within primary care were coded based on their stages of care journeys (*Diagnosis, Review, Referral, Assessment, and PR programme*) in NVivo. Meanwhile,

the understanding of HCPs' care pathways (Table 5.1) also helped map patients' care journey, for example, the consultation and referral process of patients' care journey can be speculated from HCPs' care pathways.

Based on the coding data of patients and HCPs' care pathways, the representative activities that most patients experience along their care journeys of receiving COPD treatment was summarised (see Table 5.2). Similar to the care pathways of HCPs, there are several different possible routes for patients to access PR services. Table 5.2 lists most of the representative possibilities based on the interview. In addition, the focus was only on patients' access to PR services, from diagnosis to PR and not including the PR programme itself.

Table 5.2 Patients' potential care journeys to access PR

Stages		**Diagnosis**							
Location		*Home -----> GP practice -----> Home*							
Activities		**Make an appointment with GP**	**Transport**	**Consult GP appointment**	**Referred to further check**	**checked by Nurse**	**Informed diagnosis**	**Receive Self-management treatments**	**Decide to take PR (if offered)**
Options	**1**	By telephone	Drive by oneself	N/a	Referred to practice nurse	N/a	By face-to-face	Medications (inhalers)	Not offered
	2	Drop in	Driven by family/friends		Referred to secondary care		By call	Medications (emergency pack)	Offered but declined
	3	By others	On foot		...		By letter	Pulmonary Rehabilitation (PR)	Offered and accepted
	4	By Internet	By bus+ walking		...		...	Quit smoking	...
	5	...	...		...		...	...	...

Stages		**Review**					**Referral**	
Location		*Home -----> GP practice -----> Home*					*Home*	
Activities		**Receive invitation to review**	**Transport**	**Checked by Nurse**	**Discuss care plan**	**Make a decision (PR)**	**Receive inform for referral**	**Make a decision (PR)**
Options	**1**	By letter	Drive by oneself	N/a	Offered PR	Attend	By letter	Attend
	2	By call	Driven by family/friends		Received updated medication	Not attend	By call	Not attend
	3	By message	On foot		...	...	...	...
	4	...	By bus+ walk		...	...	...	...
	5	...	...		...	...	...	...

Stages		**Assessment**					**PR**			
Location		*Home -----> Assessment avenue -----> Home*					*Home -----> PR class -----> Home*			
Activities		**Plan to get to car parking of the assessment**	**Plan to get from car parking to front reception**	**Transport**	**Assessment test**	**Make a decision (PR)**	**Plan how to get to PR class and go back**	**Transport**	**Request for Transport service**	**Continue to attend PR**
Options	**1**	By letter	By asking passerby	Drive+ walk	N/a	Attend	Ask family/friends	Drive + walk	Approved	Attend
	2	Ask friends	By calling reception	Family/friends drive		Not Attend	By memory	Transport service	Rejected	Quit
	3	By internet	By following carer	Bus		...	By satellite navigate	Walk	...	...
	4	By satellite navigate	...	Walk		...	...	Bus	...	...
	5	...	...	...		...	...	...	...	...

The similarities and differences between the care pathways of HCPs and the care journeys of patients were compared and analysed (Figure 5.6). Regarding similarities, both HCPs and patients were involved in the consultation process and decision-making. The consultation process is the interaction between HCPs and patients, in which HCPs are responsible for providing consultation and patients receive treatment. Regarding decision-making, HCPs make a clinical decision and patients decide how to respond to the treatment options.

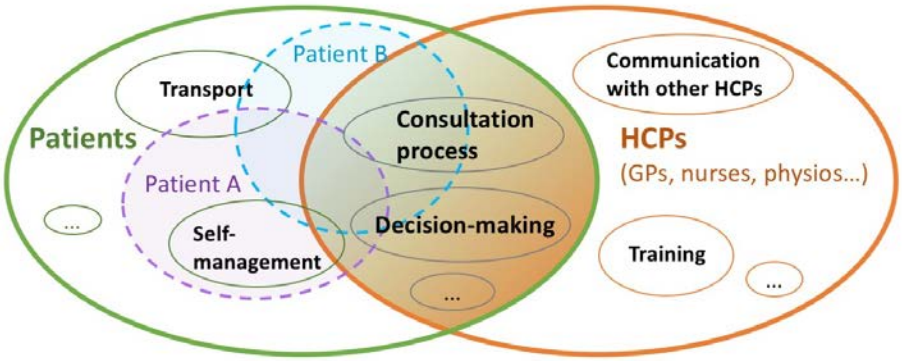


Figure 5.6 Similarities and differences between care pathways of HCPs and care journeys of patients

There are mainly four differences between patients' care journeys and HCPs' care pathways, which are also the factors that affect patients' access to PR services:

i) One patient may have to see different HCPs, e.g., GPs, nurses, and physiotherapists to receive proper care for COPD, and if the communications between the involved HCPs is not sufficient and timely complete during the process, the patient is unlikely to access care timely.

ii) Patients' care journeys are affected by some external factors, for example, patients require transport from home to care venue before they can see HCPs to access care. If there is a transportation challenge, especially when they need transport to an unfamiliar place, they may not be able to access care.

iii) To some extent, patients' care journeys may be different, even if they have the same condition and similar symptoms, depending on the information and treatments they have obtained from HCPs. For example, if the patient could be offered PR when they are diagnosed rather than later during the review, patients are more likely to be equipped with the skills to self-manage their COPD and prevent their conditions from worsening.

vi) There is a process by which patients can self-manage their COPD, although HCPs may be involved in making the self-management plan.

The capability level for the interviewed patients was calculated (see Table 5.3) based on their responses to the capabilities measure test (the questions see Appendix C9). Specifically, the capability scores of *full* refers to a person who has the full capability to do the most challenging tasks, i.e., Vision (12), Hearing (12), Mobility (12), Reach and Dexterity (12) and Thinking (12). All the scores that refer to patients with a relatively lower capability are marked in red in table 5.3. It can be inferred that people with COPD are likely to have a limited walking ability. There was no such link between people with COPD and their vision, hearing and thinking capabilities. Regarding the three interviewees that have a lower reach down capability, it was more likely due to their other conditions such as arthritis and hip pain rather than their COPD conditions. It needs to be emphasised that the analysis above was based on the interview data, which could only be used as a reference; further investigations were required to validate the inferences.

Table 5.3 Patients' potential care journeys to access PR

Personal basic info			Vision	Hearing	Thinking					Reach & Dexterity								Mobility		
Number	Age	sex (M/F)	Vison	hearing	Concentration	Remember	Literacy	Speaking Comprehension	Speaking	Lifting-strength (Dom)	Dexterity (Dom)	Reach forward &up (Dom)	Reach Down (Dom)	Lifting-strength (Non)	Dexterity (Non)	Reach forward &up (Dom)	Reach Down (Non)	Walking	Steps	Balance
Full			**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**	**12**
P1(N)	> 75	M	12	8	12	12	12	12	12	12	8	12	12	12	12	12	12	12	12	12
P2(A)	60-74	M	12	8	12	12	12	12	12	12	8	12	8	12	12	12	12	8	8	12
P3(A)	56	M	12	4	12	12	12	12	12	12	8	12	12	12	12	12	12	**4**	12	12
P4(A)	>75	M	12	8	12	12	12	12	12	12	8	12	12	12	12	12	12	**0**	12	8
P5(N)	83	M	12	4	12	12	12	12	12	12	8	12	12	12	12	12	12	12	12	12
P6(D)	60-74	F	12	8	12	12	12	12	12	12	8	12	8	12	12	12	12	12	12	12
P7(N)	69	F	12	8	12	12	12	12	12	0	8	12	12	12	12	12	12	8	12	12
P8(N)	76	M	12	12	12	12	12	12	12	12	4	12	8	12	12	12	12	12	12	12
P9(A)	65	F	12	8	12	12	12	12	12	12	8	12	12	12	12	12	12	**4**	8	4
P10(A)	60-74	F	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12
P11(A+D)	70	M	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12	12
P12(A)	60-74	M	12	4	12	12	12	12	12	12	12	12	0	12	12	12	12	**4**	8	12
P13(D)	78	F	12	12	12	12	12	12	12	12	8	12	12	12	12	12	12	**4**	12	12
P14(A+N)	80	F	12	4	12	12	12	12	12	8	12	12	12	12	12	12	12	**4**	12	12
P15(A)	60-74	M	8	12	12	12	12	12	12	8	12	12	0	12	12	12	12	**4**	12	0
P16(A)	54	M	12	12	12	12	12	12	12	12	12	12	0	12	12	12	12	12	12	12

c) Answering research question (CS2-RQ1)

The session 5.2.1.1 was designed to answer the research question, *what are the care journeys of people with COPD? (CS2-RQ1)*. Based on data from interviews with HCPs and patients, the main activities that most patients with COPD go through within primary care are summarised in Table 5.4. More detailed care journeys that patients with COPD are likely to experience

within the primary care are identified in Table 5.2. Tasks of each patient accessing the PR service depending on the options they choose are given. It is worth noting that different patients may experience different tasks along their care journeys and it is impossible to cover all the possibilities.

Table 5.4 Patients' main activities along their care journeys to access PR

Stages	Diagnosis							
Location	*Home -----> GP practice -----> Home*							
Activities	Make an appointment with GP	Transport	Consult GP appointment	Referred to further check	checked by Nurse	Informed diagnosis	Receive Self-management treatments	Decide to take PR (if offered)

Stages	Review					Referral	
Location	*Home -----> GP practice -----> Home*					*Home*	
Activities	Receive invitation to review	Transport	Checked by Nurse	Discuss care plan	Make a decision (PR)	Receive inform for referral	Make a decision (PR)

Stages	Assessment					PR			
Location	*Home -----> Assessment avenue -----> Home*					*Home -----> PR class -----> Home*			
Activities	Plan to get to car parking of the assessment	Plan to get from car parking to front reception	Transport	Assessment test	Make a decision (PR)	Plan how to get to PR class and go back	Transport	Request for Transport service	Continue to attend PR

5.2.1.2 Step 2: Estimate exclusion

Step 2 contains 3 parts: a) Estimate how demanding the COPD care journey is for patients, b) Estimate the excluded number of people, and c) Answer the research question (CS2-RQ2): *To what extent do people's capabilities affect their access to community-based PR services?*.

a) Estimate how demanding the COPD care journey is for patients

It was important to define the scope and estimate a representative care journey's demands on patients' capabilities due to the various care journeys of patients. The specific process was described below.

Define the scope and introduce the related tools

Two 'aided tools' of Inclusive Design, i.e., *personas* and *scenarios* (see Table 2.3) were used to specify the scope for estimation. Generally speaking, *personas* are fictional characters that are based on real information, each persona representing a key group of users' activities, needs, goals, behaviours, attitudes and cultural backgrounds (Nielsen, 2012). *Personas* were proposed by Cooper (1999) to equip designers with empathy for users and understand users' needs and goals when using a product. Various researchers have described the value of using personas in healthcare research, e.g., Jones (2013) described that personas are an appropriate contribution to "a care-centred design orientation, that can span the different needs of patient, professional and service, and help us define priorities for intervention and redesign". *Scenarios* describe the

stories and context of how people experience products and services. They are told from the users' point of view and are often based on one or more personas.

In this case study, a *scenario* together with a *persona* was used to define a representative care journey according to patients' real stories about accessing the PR service. Most of the user scenario in Table 5.5 are based on Mrs Smith's real stories. Some detailed descriptions from other similar patients were used to complement the scenario in order to reveal the potential challenges that prevent patients from accessing PR services.

Table 5.5 The scenario of a persona: Mrs Smith accessing PR service

Persona	Mrs Smith, a 65-years-old, retired office worker, lives with her husband in a village. She is a central hub of her family. She has a son and a daughter who is disabled and lives a mile away from her home. Mrs Smith is active, she likes shopping and gardening, but she recently felt breathlessness and could not function as before. She felt quite upset and sometimes found herself muddled in communication with friends. She was diagnosed with COPD one and a half years ago likely because of smoking. Her husband has chronic back pain.
Service name	Pulmonary rehabilitation (PR) for patients with COPD in the community
User tasks being assessed	The service's demand on patients' capability when they access PR services, mainly including representative tasks that patients are likely to be involved in: Diagnosis, Review, Referral, Assessment, and PR.
Scope	***In scope:*** This research only identifies the COPD care pathway (journey) that related to patients' access to PR services. ***Out of scope:*** Patients' ability to do exercises and take part in PR once they have accessed the service, and the PR programme were not the focus of this research. Tasks that are similar to older people's everyday activities such as make a call and open a letter are not assessed, and tasks where assistance is available are also not assessed. ***Starting point:*** The patient experience some breathing issues and books a GP appointment.
User scenario based on true stories	Here is some necessary information for the assessment: Distance from Home to GP practice: 1 km; Distance between car park and GP practice: 20-50 m. Distance from Home to Assessment/PR class (the same place as assessment): 30km; Distance between car park and Assessment/ PR class: 300m. PR programme: 8 weeks programme, which contains 16 sessions and two sessions a week. Each session involves about an hour for exercise and half an hour for education, and a tea break between exercise and education. ***Diagnosis*:** Mrs Smith had a sign of asthma and became breathlessness, so she decided to see her GP. She made a GP appointment by telephone, and she needed to put on her hearing aid as her left ear is impaired. Although the GP practice was not far from her home, Mrs Smith went there by car. She parked and signed in through the self-check counter. The GP asked her symptoms and referred her to further check by the practice nurse. The nurse asked her to do some tests such as the spirometry test and measured her blood pressure to help the diagnosis. Then, she returned home and waited for the further information. About five days later, she received a letter from the GP practice which informed her she had COPD. She was shocked because she had no idea what COPD was, and there was no more information offered to her in the letter. She was particularly distraught because she has a history of depression. It took her about two weeks to calm down before she phoned the nurse for further consultation. However, the nurse in the GP practice she called did not have much knowledge about COPD care, and she just received two inhalers (medications) for the treatment and was advised to quit smoking without further help. At home, she found it difficult to read the instruction of one inhaler, because the font size was too small. Also, she found her vision declined, and her eye doctor suggested she change her glasses. She thought the inhaler had side effects and could lead to cataracts. ***Review*:** Ten months after the diagnosis, Mrs Smith received an invitation letter for a COPD annual review. As usual, she went to the review by car, and her husband accompanied her as they were looking for more information to help her condition. They arrived a little bit late, so she had to sign in through the reception. The nurse (who was not the same as the one who did the diagnosis) did the annual check, reviewed the medication, assessed her COPD condition. Mrs Smith wanted to keep active, and she asked the nurse whether she could go swimming. The nurse asked Mrs Smith, "why didn't you go for PR?", and the nurse suggested she try the PR which contained exercise and education. She felt a bit sad as she was not offered PR when she was diagnosed, and the nurse seemed not to know her and her condition. She wondered whether the nurse could tell her a bit more information, but the nurse did not have a PR leaflet available. Regardless of that, Mr Smith encouraged his wife to have a try, so she decided to have a go.

Table 5.5 The scenario of a persona: Mrs Smith accessing PR service (continued)

User scenario based on true stories	***Referral*:** About one week later, Mrs Smith received the referral letter, which included an appointment for assessment and a leaflet about PR. She was quite happy about the opportunity to do some exercise, so she decided to go. ***Assessment*:** The assessment venue was quite far away, so she asked her husband to drive. There were no detailed navigation instructions like a map in the invitation letter, so they had to plan the transport route by entering the postcode from the invitation letter into the car's GPS system. However, it was not easy to find the assessment venue from the car park, due to the limited mobility. Mrs Smith stayed in the car while her husband wandered around to find the reception. Then her husband came back to pick up Mrs Smith once he had sorted it out. As a result, it took them a while to find the front reception. The physiotherapist did the assessment for her, which included questionnaires, a review of her medication, and a walking test, etc. Mrs Smith worried that she could not make two times a week as the class was very early in the morning, so she tended to say No. Luckily, the physiotherapist who was very considerate, tailored the class schedule for Mrs Smith, i.e., one session per week instead of two sessions per week. She was very pleased with the customised plan, so she decided to attend the PR class. However, due to the limited space in the PR class, she had to wait about two months to start her class. During the waiting period, Mrs Smith had a difficult time since her condition had become worse. She often felt depressed because she was not able to do daily activities as she used to. ***PR*:** The PR class starts at 9 am and finishes at 11 am, so Mrs Smith had to get up quite early. She drove by herself as her husband's back pain had worsened and she already knew where the PR class was. She arrived at the car park of the PR class and walked to the reception. However, there were about 300 metres away from the car park to the classroom. She had to stop and rest several times on the way because 50 metres is the furthest distance she can walk without needing to stop due to discomfort. When she arrived at the classroom, she felt a bit tired, which prevented her from effectively taking part in the exercises. After attending a few times, Mrs Smith noticed that some people had the transport service, so she requested the transport service. However, the PR provider rejected her application for the transport service due to the limitation of the service, which is only available to people who live very far and could not drive. As a consequence, she decided to quit the PR service as she did not want to be a burden to her family (to get there) but going by herself was too onerous.

There were two reasons why the care journey of Mrs Smith and people similar to her was selected as a prototype to assess the PR service's demands on patients. Firstly, Mrs Smith had accepted a PR offer and experienced all five stages of the COPD care. Secondly, Mrs Smith's situation could be used to gain insights into why some people with COPD are not referred or decline since they cannot access the PR services. The main difference in care journeys between people who are not referred or decline and people who accept PR is that those people who are not referred or decline only experience part of the primary COPD care journey, signalling challenges along the COPD care journey that prevent them from accessing PR services (see Figure 5.7). Therefore, Mrs Smith's case would be a representative care journey to estimate the capability demand and understand the potential challenges along patients' care journey.

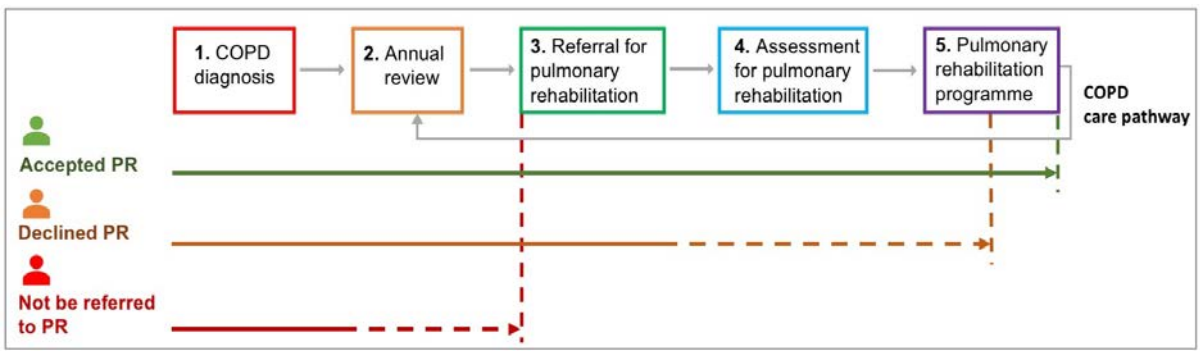


Figure 5.7 The main difference of care journeys between different patients' categories

According to Mrs Smith's scenario, the way (option) of Mrs Smith and patients similar to her conducting each activity was defined and marked in blue in Table 5.6, which could be used to further specify tasks for assessment (see Table 5.7).

Table 5.6 The activity based on Mrs Smith's care journey accessing PR service

Stages		Diagnosis							Annual review				
Location		*Home -----> GP practice -----> Home*							*Home -----> GP practice -----> Home*				
Activities		Transport	Consult GP appointment	Referred to further check	checked by Nurse	Informed diagnosis	Receive treatment	Decide to take PR (if offered)	Receive invitation to review	Transport	Checked by Nurse	Discuss care plan	Make a decision (PR)
Options	1	Drive by oneself	N/a	Referred to practice nurse	N/a	By face-to-face	Medications (inhalers)	Not offered	By letter	Drive by oneself	N/a	Offered PR	Attend
	2	Driven by family/ friends		Referred to secondary care		By call	Medications (emergency pack)	Offered but declined	By call	Driven by Family/ friends		Received updated medication	Not attend
	3	On foot		...		By letter	Pulmonary Rehab (PR)	Offered and accepted	By message	On foot		...	...
	4	By bus+ walk		...		...	Quit smoking	...	...	By bus+ walk		...	...
	5	...		...		...	...	...	...	...		...	...

Stages		Referral		Assessment					PR			
Location		*Home*		*Home -----> Assessment avenue -----> Home*					*Home -----> PR class -----> Home*			
Activities		Receive inform for referral	Make a decision (PR)	Plan to get to the assessment avenue	Transport	Find assessment venue from the parked car	Assessment test	Make a decision (PR)	Transport	PR class ...	Request for Transport service	Continue to attend PR
Options	1	By letter	Attend	By letter	Drive by oneself + walk	By calling reception	N/a	Attend	Drive by oneself + walk	N/a	Approved	Attend
	2	By call	Not attend	By car's satellite navigate	Drive by Family/ friends + walk	Family/friends' help		Not Attend	Transport service		Rejected	Quit
	3	...	...	Ask friends	Bus	Asking passerby		...	Walk		...	...
	4	...	...	By internet	Walk	...		...	Bus		...	...
	5	...	...	...	...	...		...	...		...	...

Estimate demand

The tasks were further specified (see Table 5.7) and checked by a senior researcher specialised in Inclusive Design to make sure the categories were reasonable. The level of the tasks' description matched against the pre-defined scales (see Appendix B4), which were constructed based on the questions in the Disability Follow-up to the Family Resources Survey, to assess the demand of every task. All the specific tasks matched with the scenario and tasks used for assessment were marked in blue colour in Table 5.7. Tasks that were similar to older people's everyday activities such as "*receive the letter*" and "*find directions-drive-park*" were not included in the assessment. Also, tasks where assistance was available were also not included as well, e.g., the task "*chest check*" which was more reliant on the GP and patients could obtain the relevant assistance.

Table 5.7 The specified tasks based on Mrs Smith's care journey accessing PR service

Stage	Diagnosis							
No.	1	2	3	4	5		6	7
Activities	**Transport *(drive by herself* to GP practice)**	**Consult GP appointment**	**Referred to practice nurse**	**Checked by Nurse**	**Informed diagnosis *(by letter)***	**Gap**	**Receive treatment *(inhalers)***	**Receive Limited treatment option**
Specific tasks (in sequence)	Find directions-Drive-Park	Describe symptoms	Wait 20 mins	Describe symptoms	Receive the letter	No information about COPD, feel depressed and anxious.	Open the package	Not offered PR at the start;
	Walk	Chest check	Go to the nurse's office	Spirometry test	Read letter		Read the instructions	Not offered enough support to quit smoking
	…	Breath with stethoscope	…	…	…		Use the inhalers	…

Stage	Review					Referral	
No.	1	2	3	4	5	1	2
Activities	**Receive invitation to review (By letter)**	**Transport *(drive* to GP practice)**	**Checked by Nurse**	**Discuss care plan (offered PR)**	**Make a decision (attend PR)**	**Receive inform for referral (by letter)**	**Make a decision (attend PR)**
Specific tasks (in sequence)	Receive the letter	Find directions-Drive-Park	Answer questions for review	Offered the PR class	Discuss with families	Receive the letter	Confirm the date for assessment and mark in diary
	Read letter	Walk	Do COPD Assessment Test	Requested information about PR	Agree the attendance	Read letter	
	Confirm the date and mark in diary		Do spirometry test				

Stage	Assessment				Pulmonary Rehabilitation (PR)			
No.	1	2	3	4	1	2	3	4
Activities	**Plan to get to car parking of the assessment (by letter+ satellite navigate)**	**Transport from car parking to front reception**	**Assessment test**	**Make a decision (Attend PR)**	**Transport from home to the car parking (Drive by herself)**	**Transport from car parking to PR class (walk)**	**Request for transport service(rejected)**	**Continue attending PR**
Specific tasks (in sequence)	Ask her husband to help drive	Walk 50m and stop 4-5 times to rest (in total 300m)	Provide invitation and medication to be checked	Obtain more information about PR	Drive to the same place of assessment	Walk 50m and stop 4-5 times to rest (in total 300m)	Find out about the transport service	Decide to quit
	Read the instructions for travel in referral letter		Fill in questionnaires	Request to tailor the class schedule			Request transport service	
	Input postcode into car's GPS system		Walking test	Obtain the tailored class schedule			Reject the application	
				Agree and wait for attendance				

Similar to case study 1, the demand of every task was evaluated by pre-defined scales (Table 5.8). Generally, a higher demand on people's capabilities leads to higher scale ratings, and the symbol ">" (off scale) which means it is excessive for a mainstream service for people to access. There were seven times rated ">" on patients' capabilities, including four times rated ">" on patients' *vision*, twice rated ">" on patients' *literacy*, one time rated ">" patients' *memory*. For example, the capability *vision and literacy* rated ">" of task 6 "*read letter* (Informed diagnosis by letter)" due to lack of information about COPD for patients to read in the diagnosis letter. Although the rated score for *walking* capability in task 18, task 27 and task 30 was rated only "10" (marked in red colour), it was still most likely to beyond the walking capability of patients with COPD. The last column of the table shows the overall demands of all the tasks.

Table 5.8 Demand on every task of PR service based on Mrs Smith's scenario

Stage		Diagnosis								
Task No.		1	2	3	4	5	6	7	8	9
Task name		Walk	Describe symptoms	Wait 20 mins	Go to the nurse's office	Describe symptoms	Read letter	Open the package (inhalers)	Read the instructions (inhalers)	Use the inhalers
	Vision	12	0	0	10	0	>	10	>	10
	Hearing	4	8	4	0	8	0	0	0	0
	Concentration	4	4	4	4	4	0	4	8	8
	Memory	8	8	4	0	8	0	0	12	12
	Literacy	4	0	0	4	0	>	4	8	0
	Speech Comp.	0	8	4	0	8	0	0	0	0
	Speaking	0	12	4	0	12	0	0	0	0
	Strength	0	0	0	0	0	0	0	0	3
	Dexterity	0	0	0	0	0	0	0	0	4
	Forward/Up	0	0	0	0	0	0	0	0	6
	Down	0	0	0	0	0	0	0	0	0
	Strength	0	0	0	0	0	1	1	1	0
	Dexterity	0	0	0	0	0	8	8	8	0
	Forward/Up	0	0	0	0	0	4	4	4	0
	Down	0	0	0	0	0	0	0	0	0
	Walking	4	0	0	2	0	0	0	0	0
	Stairs	0	0	0	0	0	0	0	0	0
	Standing	0	0	0	0	0	0	0	0	0

Stage		Review					Referral
Task No.		10	11	12	13	14	15
Task name		Read the letter	Walk	Answer questions for review	Offered the PR class	Request information about PR	Read the letter
	Vision	12	12	0	0	>	0
	Hearing	0	4	8	8	8	0
	Concentration	4	4	8	8	8	4
	Memory	12	8	12	12	0	12
	Literacy	12	4	0	0	>	12
	Speech Comp.	0	0	8	8	8	0
	Speaking	0	0	12	12	12	0
	Strength	0	0	0	0	0	0
	Dexterity	0	0	0	0	0	0
	Forward/Up	0	0	0	0	0	0
	Down	0	0	0	0	0	0
	Strength	1	0	0	0	0	1
	Dexterity	8	0	0	0	0	8
	Forward/Up	4	0	0	0	0	4
	Down	0	0	0	0	0	0
	Walking	0	4	0	0	0	0
	Stairs	0	0	0	0	0	0
	Standing	0	0	0	0	0	0

Table 5.8 Demand on every task of PR service based on Mrs Smith's scenario (continued)

Stage		Assessment									
Task No.		16	17	18	19	20	21	22	23	24	25
Task name		Ask her husband to help drive	Read the instructions for travel in referral letter	Walk and stop to rest after every 50m of walking (in total 300m distance)	Provide invitation and medication to be checked	Fill in question-aires	Walking test	Obtain more info about PR	Request to tailor the class schedule	Obtain the tailored class schedule	Agree and wait to attend
	Vision	0	>	12	0	12	10	0	0	0	0
	Hearing	8	0	0	8	0	8	8	8	8	0
	Concentration	4	8	4	8	10	12	8	8	4	0
	Memory	0	0	0	12	12	0	0	0	12	>
	Literacy	0	8	4	0	8	0	0	0	0	0
	Speech Comp.	8	0	0	8	8	8	8	8	8	0
	Speaking	8	0	0	12	8	8	8	8	0	0
	Strength	0	0	0	2	2	0	0	0	0	0
	Dexterity	0	6	0	0	0	0	0	0	0	0
	Forward/Up	0	4	0	4	4	0	0	0	0	0
	Down	0	0	0	0	0	0	0	0	0	0
	Strength	0	0	0	0	0	0	0	0	0	0
	Dexterity	0	0	0	0	0	0	0	0	0	0
	Forward/Up	0	0	0	0	0	0	0	0	0	0
	Down	0	0	0	0	0	0	0	0	0	0
	Walking	0	0	10	0	0	0	0	0	0	0
	Stairs	0	0	0	0	0	0	0	0	0	0
	Standing	0	0	0	0	0	0	0	0	0	0

Stage		PR					Overall demand
Task No.		26	27	28	29	30	
Task name		Drive to the same place of assessment	Walk and stop 4-5 times to rest (in total 300m)	Find out about the transport service	Request transport service	Decide to quit	
	Vision	12	12	8	0	12	>
	Hearing	8	0	0	8	8	8
	Concentration	12	4	4	4	12	12
	Memory	12	0	4	12	12	>
	Literacy	4	4	0	0	4	>
	Speech Comp.	0	0	0	8	0	8
	Speaking	0	0	0	8	0	12
	Strength	8	0	0	0	8	8
	Dexterity	4	0	0	0	4	6
	Forward/Up	6	0	0	0	6	6
	Down	0	0	0	0	0	0
	Strength	8	0	0	0	8	8
	Dexterity	4	0	0	0	4	8
	Forward/Up	6	0	0	0	6	6
	Down	0	0	0	0	0	0
	Walking	0	10	0	0	10	10
	Stairs	0	0	0	0	0	0
	Standing	0	0	0	0	0	0

b) Estimate the excluded number of people

There were two ways to estimate the exclusion number of people who could not be able to access PR: i) using the British population database within the current "Exclusion Calculator" to measure exclusion of general people's (some of them may have COPD) access to PR services; ii) screening the capability data of people with COPD from the available British population database and estimate the exclusion of people with COPD when they access PR services.

Similar to case study 1, the "Exclusion Calculator" (an Inclusive Design tool) was used to estimate the proportion of the British population (Great Britain) that was unable to use PR service because of the demands that it places on people's capability (EDC, 2007). By inputting the estimated demands (rated scale) of each task along the COPD care journey, the "Exclusion Calculator" can estimate the number of people within the general population excluded from accessing PR (in every task and on the whole care journey). It is important to clarify that the exclusion number was based on Mrs Smith's scenario, which referred to the estimated number of patients who have capabilities and a care journey similar to Mrs Smith and are likely to be excluded.

Overall, based on the PR service' demands on patients' capability, about 15.6% of British people who experience a similar scenario to Mrs Smith could be excluded from the PR service (Table 5.9). Although the exclusion number from the calculator is based on the general population (rather than those with COPD), we can still obtain insights into challenges raised by the COPD care journeys from the exclusion levels predicted. For example, the demand on the *mobility* of patients with COPD was the highest among all the capabilities (9.9%), especially during the stage of *assessment* and *PR*. Also, the calculator may underestimate the level of exclusion of some tasks since a loss in capability may not be due to COPD, but it could still provide useful insights. For instance, people with arthritis may have a declined capability in *reach and dexterity*, so the exclusion may increase when those people access the PR service.

Table 5.9 The exclusion of every stage (based on Table 5.5 Mrs Smith's scenario)

Stage	Diagnosis	Review	Referral	Assessment	PR	Overall exclusion
Exclusion (%)	12.6%	12.3%	8.9%	14.8%	15.3%	15.6%
Vision only (%)	4.1%	4.1%	4.1%	4.1%	4.1%	4.1%
Hearing only (%)	2.3%	2.3%	0.0%	2.3%	2.3%	2.3%
Thinking only (%)	4.6%	4.6%	3.0%	5.2%	5.0%	5.3%
Reach & dex only (%)	5.7%	4.8%	4.8%	3.2%	5.4%	6.1%
Mobility only (%)	4.7%	4.7%	0.0%	9.9%	9.9%	9.9%

Based on the scenario, the detailed exclusion of every task was rated and entered in Table 5.10. The highest excluded task in each stage was marked in red. For example, the highest excluded task among those in the *diagnosis* stage was No.8"*Read the instructions* (inhalers)", as the font size of the inhaler's instruction was too small to read (smaller than the original newspaper's font which rated *12*). In the PR stage, the exclusion number among the activities in task No.30 "*Decide to quit* (PR)" was the highest, due to the demand on patients' capability when driving and walking to the class venue (300m is far beyond what a person who needs rest when every 50m can manage). The last column of each stage shows the overall exclusion in that stage. And the data of every task's exclusion could assist in step 3 in identifying challenges.

Table 5.10 The exclusion of every task and each stage (based on Table 5.5 Mrs Smith's scenario)

Stage	Diagnosis									
Task NO.	1	2	3	4	5	6	7	8	9	Overall exclusion
Exclusion (%)	8.9%	4.4%	2.7%	4.9%	4.4%	7.7%	7.2%	9.4%	7.0%	12.6%
Vision only (%)	4.1%	0.0%	0.0%	2.6%	0.0%	4.1%	2.6%	4.1%	2.6%	4.1%
Hearing only (%)	1.1%	2.3%	1.1%	0.0%	2.3%	0.0%	0.0%	0.0%	0.0%	2.3%
Thinking only (%)	1.7%	2.7%	1.7%	1.4%	2.7%	0.8%	1.4%	3.6%	3.4%	4.6%
Reach & dex only (%)	0.0%	0.0%	0.0%	0.0%	0.0%	4.8%	4.8%	4.8%	2.8%	5.7%
Mobility only (%)	4.7%	0.0%	0.0%	2.4%	0.0%	0.0%	0.0%	0.0%	0.0%	4.7%

Stage	Review						Referral	
Task NO.	10	11	12	13	14	Overall exclusion	15	Overall exclusion
Exclusion (%)	8.9%	8.9%	5.7%	5.7%	7.9%	12.3%	8.9%	8.9%
Vision only (%)	4.1%	4.1%	0.0%	0.0%	4.1%	4.1%	4.1%	4.1%
Hearing only (%)	0.0%	1.1%	2.3%	2.3%	2.3%	2.3%	0.0%	0.0%
Thinking only (%)	3.0%	1.7%	4.3%	4.3%	3.9%	4.6%	3.0%	3.0%
Reach & dex only (%)	4.8%	0.0%	0.0%	0.0%	0.0%	4.8%	4.8%	4.8%
Mobility only (%)	0.0%	4.7%	0.0%	0.0%	0.0%	4.7%	0.0%	0.0%

Stage	Assessment										
Task NO.	16	17	18	19	20	21	22	23	24	25	Overall exclusion
Exclusion (%)	3.9%	7.9%	12.1%	6.7%	8.2%	7.5%	4.9%	4.9%	4.6%	1.6%	14.8%
Vision only (%)	0.0%	4.1%	4.1%	0.0%	4.1%	2.6%	0.0%	0.0%	0.0%	0.0%	4.1%
Hearing only (%)	2.3%	0.0%	0.0%	2.3%	0.0%	2.3%	2.3%	2.3%	2.3%	0.0%	2.3%
Thinking only (%)	2.0%	2.8%	1.4%	4.3%	4.6%	4.6%	3.3%	3.3%	3.0%	1.6%	5.2%
Reach & dex only (%)	0.0%	3.2%	0.0%	1.6%	1.6%	0.0%	0.0%	0.0%	0.0%	0.0%	3.2%
Mobility only (%)	0.0%	0.0%	9.9%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	9.9%

Stage	PR					
Task NO.	26	27	28	29	30	Overall exclusion
Exclusion (%)	11.1%	12.1%	2.4%	4.8%	15.2%	15.3%
Vision only (%)	4.1%	4.1%	1.1%	0.0%	4.1%	4.1%
Hearing only (%)	2.3%	0.0%	0.0%	2.3%	2.3%	2.3%
Thinking only (%)	4.4%	1.4%	1.4%	3.2%	4.4%	5.0%
Reach & dex only (%)	5.4%	0.0%	0.0%	0.0%	5.4%	5.4%
Mobility only (%)	0.0%	9.9%	0.0%	0.0%	9.9%	9.9%

In terms of the second way of estimating the exclusion, it is necessary to review the available population data. As introduced in Chapter 2 (page 37), the original population data (sample size n=7618) was taken from the Disability Follow-up to the Family Resources Survey (Grundy *et al*., 1999). The survey was based on the Great British adult population living in private households, which was 43.3 million people at the time of the survey. Among these participants, 126 participants have COPD and 962 participants self-reported that they have a respiratory issue, and it is likely that a significant number of these people could benefit from PR. A senior respiratory specialist from CUH filtered the data from the whole population data to ensure rationality. It was considered meaningful to screen those people's capability data and measure the exclusion of people with COPD as well as those who have a respiratory issue when they access the PR service.

Table 5.11 shows the exclusion of people with COPD based on the DFS population database. Overall, about 82.1% of people with COPD were unlikely to access the PR service due to the service's demand on their capabilities. The exclusion caused by mobility demand of the PR service on patients was the highest among all the capabilities, accounting for 64.4%, which indicated the importance of understanding and considering the mobility demand of people with COPD when they access a PR service.

Table 5.11 The exclusion of people with COPD based on the DFS population database (1997)

Category	Vision	Hearing	Thinking					Reach & Dexterity								Mobility			Exclusion calculation		
Capability and related exclusion	Vison	Hearing	Concentration	Remember	Literacy	Speaking Comprehension	Speaking	Lifting-strength (Dom)	Dexterity (Dom)	Reach forward &up (Dom)	Reach Down (Dom)	Lifting-strength (Non)	Dexterity (Non)	Reach forward &up (Dom)	Reach Down (Non)	Walking	Steps	Balance	People with COPD within the population database in 1997 (43309907)	Excluded population of people with COPD	Percentage excluded (people with COPD)
Capability demand	>	8	12	>	>	8	12	8	6	6	0	8	8	6	0	10	0	0			
Overall exclusion	12	8	12	12	12	8	12	8	6	6	0	8	8	6	0	10	0	0	180,786	148,471	82.1%
Vision only	12	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	180,786	30,405	16.8%
Hearing only	0	8	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	180,786	25,431	14.1%
Thinking only	0	0	12	12	12	8	12	0	0	0	0	0	0	0	0	0	0	0	180,786	47,562	26.3%
Reach & dex only	0	0	0	0	0	0	0	8	6	6	0	8	8	6	0	0	0	0	180,786	46,047	25.5%
Mobility only	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	0	0	180,786	116,346	64.4%

The exclusion of those people with a respiratory issue when accessing PR was calculated as well (Table 5.12). About 65.3% of people with a respiratory problem may be excluded from the PR service. Similar to people with COPD, the exclusion made by the demand on patients' mobility was the highest among those people who self-reported a respiratory condition, making

up 47.1%. The demand on hearing capability caused relatively lower exclusion compared the demand on other capabilities.

Table 5.12 The exclusion of people with respiratory issue based on the DFS population database (1997)

Category	Vision	Hearing	Thinking					Reach & Dexterity								Mobility			Exclusion calculation		
Capability and related exclusion	Vison	Hearing	Concentration	Remember	Literacy	Speaking Comprehension	Speaking	Lifting-strength (Dom)	Dexterity (Dom)	Reach forward &up (Dom)	Reach Down (Dom)	Lifting-strength (Non)	Dexterity (Non)	Reach forward &up (Dom)	Reach Down (Non)	Walking	Steps	Balance	People with respiratory issue within the population database in 1997 (43,309,907)	Excluded population of people with respiratory issue	Percentage excluded (people with respiratory issue)
Capability demand	>	8	12	>	>	8	12	8	6	6	0	8	8	6	0	10	0	0			
Overall exclusion	12	8	12	12	12	8	12	8	6	6	0	8	8	6	0	10	0	0	1,439,984	940,616	65.3%
Vision only	12	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1,439,984	238,555	16.6%
Hearing only	0	8	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1,439,984	131,207	9.1%
Thinking only	0	0	12	12	12	8	12	0	0	0	0	0	0	0	0	0	0	0	1,439,984	320,986	22.3%
Reach & dex only	0	0	0	0	0	0	0	8	6	6	0	8	8	6	0	0	0	0	1,439,984	360,084	25.0%
Mobility only	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	0	0	1,439,984	678,326	47.1%

In addition, the exclusion proportion of people with COPD based on the capabilities of the 16 interviewed patients was calculated (Table 5.13). Among the interviewed patients, about 62.5% of people with COPD may be excluded from the PR service. Declined mobility was the main factor that prevents people from accessing PR services. Although the exclusion number of thinking capability is 0, this does not illustrate that thinking capability does not affect people's access to PR since the number of interviewed patients was small as a result of limited time and available resources.

Table 5.13 The exclusion of people with COPD based on the interviewed patients

Category	Vision	Hearing	Thinking					Reach & Dexterity								Mobility			Exclusion calculation		
Capability and related exclusion	Vison	Hearing	Concentration	Remember	Literacy	Speaking Comprehension	Speaking	Lifting-strength (Dom)	Dexterity (Dom)	Reach forward &up (Dom)	Reach Down (Dom)	Lifting-strength (Non)	Dexterity (Non)	Reach forward &up (Dom)	Reach Down (Non)	Walking	Steps	Balance	People with COPD based on the interview data	Excluded population of people with COPD based on the interviewed patients	Percentage excluded (people with COPD)
Capability demand	>	8	12	>	>	8	12	8	6	6	0	8	8	6	0	10	0	0			
Overall exclusion	12	8	12	12	12	8	12	8	6	6	0	8	8	6	0	10	0	0	16	10	62.5%
Vision only	12	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	16	1	6.3%
Hearing only	0	8	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	16	4	25%
Thinking only	0	0	12	12	12	8	12	0	0	0	0	0	0	0	0	0	0	0	16	0	0
Reach & dex only	0	0	0	0	0	0	0	8	6	6	0	8	8	6	0	0	0	0	16	2	12.5%
Mobility only	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	10	0	0	16	8	50.0%

Figure 5.8 presents the exclusion proportion based on the three different groups' capabilities, i.e., *Group 1:* people with COPD within the British population database; *Group 2:* people with a respiratory issue within the British population database, and *Group 3:* people with COPD

within the 16 interviewed patients. The mobility exclusion was the highest of all the three groups, and the overall exclusion number was very high, which suggests the importance of considering capability-related needs of patients with COPD to improve their access to care.

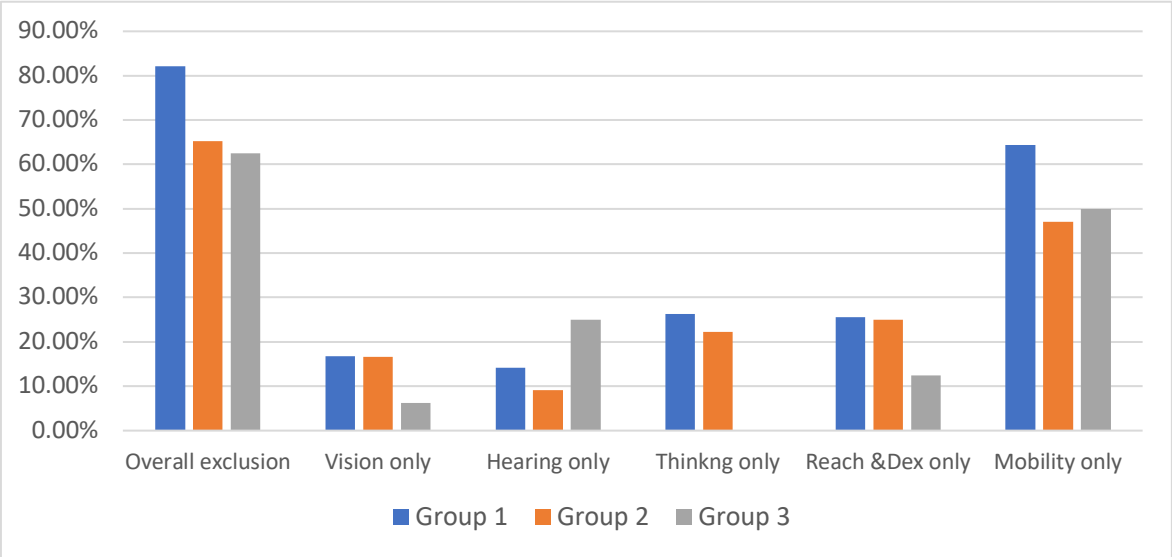


Figure 5.8 The exclusion number based on three different groups' capabilities

Regarding this calculation, it is important to clarify that the overall demand on *Vision, Remember, and Literacy* was rated ">", but the scale "12" (marked in red colour in Table 5.11, 5.12 and 5.13) was used instead of ">" due to the range of application of the available capability data within DFS. The DFS data can be used to calculate how many people would be excluded by a product/service with a particular set of demands. However, if demands are made by some products or services over the level of capability that is measured in the DFS survey, then the Exclusion Calculator would not be able to assess the demand (Appendix C9).

c) Answering the research question (CS2-RQ2)

The purpose of estimating exclusion was to answer the research question (CS2-RQ2), *to what extent do people's capabilities affect their access to community-based PR services?* A representative user scenario was created to define a representative care journey for patients accessing the community-based PR service in Cambridge city. The accessibility of the service was evaluated through task analysis and exclusion calculation. Tasks which placed a higher demand on patients' capabilities were identified. These included "*read the instructions of inhalers* (task 8)" in the diagnosis stage, "*transport from car park to assessment's venue* (task 18)" in the assessment stage, and "*decide to quit PR* (task 30)" in the PR stage.

It was estimated that at least 15.6% of the British population and 82.1% of people with COPD are likely to be excluded from PR services based on Mrs Smith's scenario. In particular,

people's mobility capability has a greater impact in deciding whether they can the access PR services. It is necessary to emphasise that this Exclusion Calculator was based on a representative patient care journey, not covering all the possibilities; and even on the same care journey, different people have different capabilities to respond to the demand. Nevertheless, the exclusion could inform of potential challenges caused by the service's demand on patients' capabilities. Overall, the analysis in step 2 provides evidence that people's access to PR services is potentially limited when the demands lie beyond their capabilities to respond.

5.2.1.3 Step 3: Identify challenges

The challenges of accessing PR were identified in two ways: further analysing the interview data with HCPs and patients; and consulting the data about PR care journeys' demands on patients and the excluded number of people. Meanwhile, some initial recommendations were proposed to address these challenges and improve patients' access to PR services. Specifically, step 3 includes three parts: a) Analysis of interview data, b) Proposing initial recommendations, and c) Answering research questions (CS2-RQ3). The detailed process is outlined below:

a) Analysis of interview data

The analysis of interview data included two parts: *method and tools for data analysis* and *output of data analysis*.

Method and tools for data analysis

Framework analysis (Smith and Firth, 2011), which enables themes to be developed both inductively from the experiences and views of participants and deductively from existing literature (tools and theories of Inclusive Design and service design), was used to structure the data analysis of interview transcripts. Table 5.14 describes the stages and process of the *framework analysis*.

Table 5.14 Overview of the framework analysis (adapted from Ritchie and Lewis, 2003)

Stages	Data management	Descriptive accounts	Explanatory accounts
Process	- Becoming familiar with the raw data - Identifying initial codes/ categories/themes - Developing coding matrix - Assigning data to the coding matrix	- Summarising and synthesising the range and diversity of coded data by refining initial codes/categories/themes - Distilling more abstract concepts and themes	- Developing associations/ patterns within concepts and themes - Interpreting and explaining the concepts and themes - Seeking wider applications

In the *data management* stage, firstly, all the raw data was familiar and managed in NVivo 12, and then initial codes and categories were created based on the research questions and five

participants' transcripts (Table 5.15). The initial codes and their definitions were checked by a senior researcher of EDC and a researcher of CUH to make sure they minimised bias and were understandable.

Table 5.15 The initial themes and codes (v1.0) for analysing interview data

Initial categories	Initial Codes (called nodes in NVivo)
Capability	Vision, Hearing, Thinking, Reach& Stretch, Dexterity, Mobility, Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADLs)
Main stage of care pathway(journey)	COPD Diagnosis, Annual Review, PR referral, Assessment for PR, PR Programme
Care related	Care Journey, Care pathway, Healthcare professionals (HCPs), Decision-making (HCP), Decision-making (patients), Challenges of HCPs, Challenges of patients, HCPs' perceptions about PR, Patients' perceptions about PR, Patients' needs (HCPs), Patients' experience
Clinical	Symptoms, Tests of health, Medication, Mental (ill) Health, Self-care, Smoking, Outcome
Personal characteristics	Motivation, Sociability, Expectation, Confidence, Emotion, Multi-morbidity(conditions), Patients' information (health and care record)
Barriers	Time and timing, Location, Transport, Safety, Information channel
Support Networks	Apps, Personal support network, Organisation support network

Subsequently, three service design tools, i.e., *user journey's map*, *service blueprint*, and *experience map,* were drawn on to help to refine the codes' list and develop the coding matrix.

User journey maps view the individual as a user (customer) of the service/product, which tell the story of the user's experience within a specific journey. It should identify the key interactions (activities) of the user with products/services, and this information could be used to improve the journey and remove barriers. A template of the user journey map is presented in Figure 5.8. The user journey maps may vary depending on the specific context for which they are used; they tend to follow a general model that includes zones for the lens, the mapped experience and the insights learned throughout the process. See Figure 5.9 below for the explanation.

Zone A: The lens provides constraints for the map by assigning (1) a persona ("who") and (2) the scenario to be examined ("what").

Zone B: The heart of the map is the experience, usually aligned across (3) phases of the journey, (4) actions, (5) thoughts, and (6) emotional experience of the user throughout the journey. Zone C: The output should vary based on the goal that the map supports, but it could describe the insights and pain points discovered, and the (7) opportunities to focus on going forward, as well as (8) internal ownership (Nielsen Norman Group, 2016).

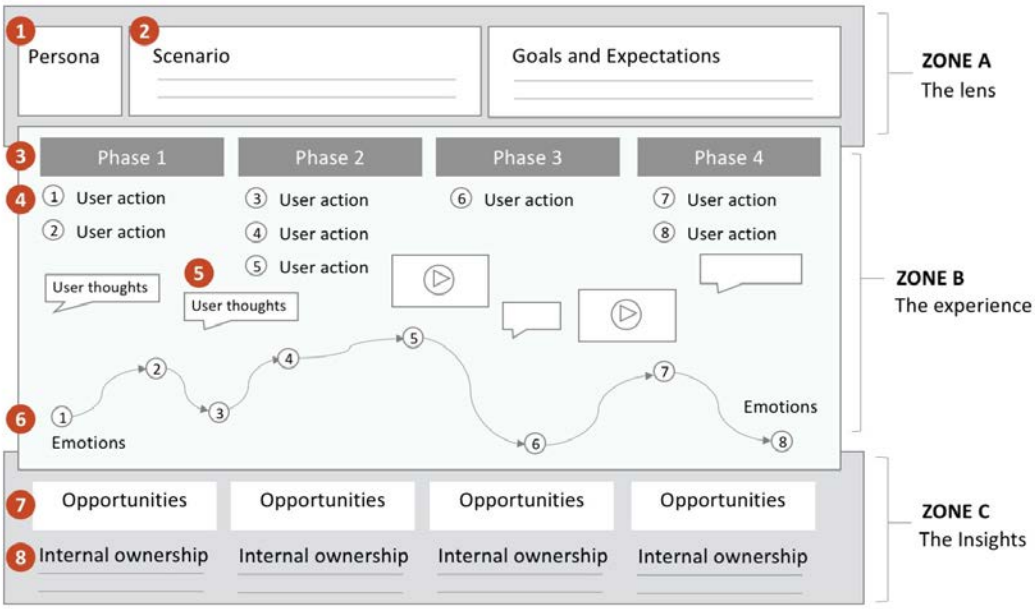


Figure 5.9 Deconstruction of a user journey map (Nielsen Norman Group, 2016)

Combining the third research question (i.e., *How can we use the principle of Inclusive Design to improve people's access along their PR journeys*), the elements of the user journey map specified and focused on the capabilities-related experiences and insights. Figure 5.10 shows an example of an Inclusive approach to a user journey map, which was based on Mrs Smith' care journey.

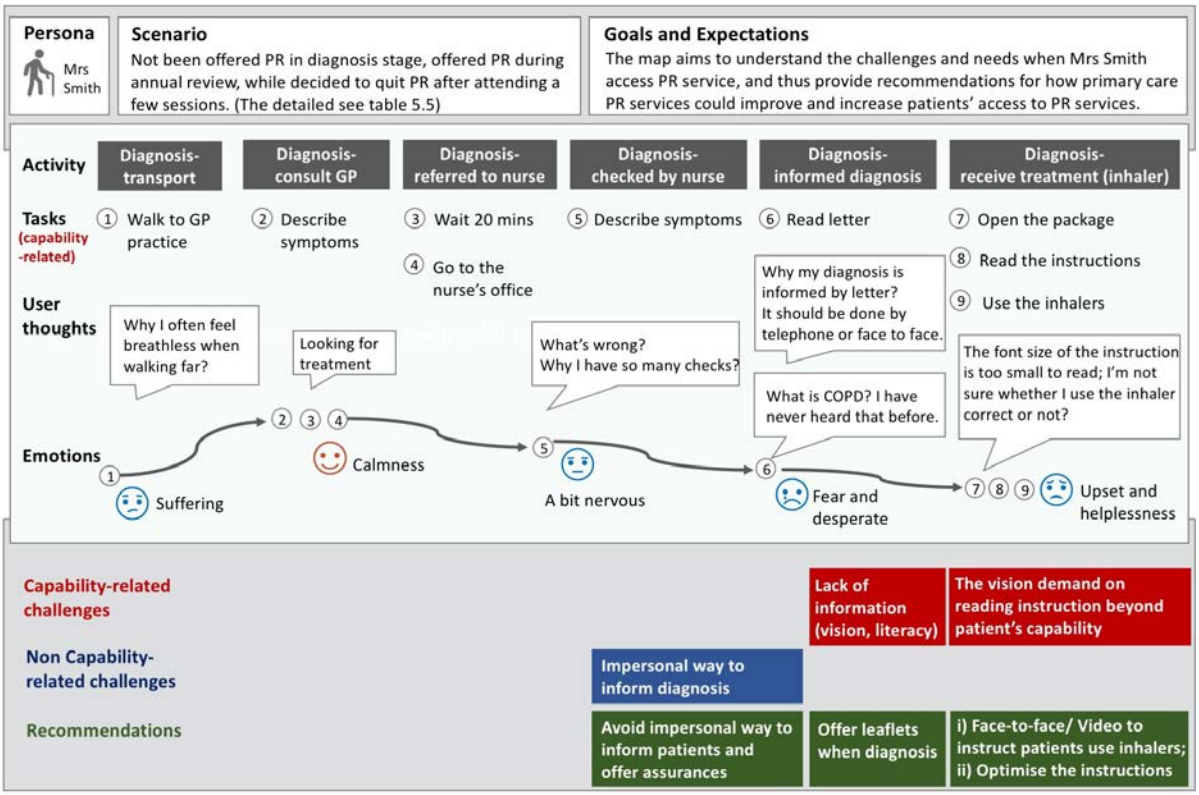


Figure 5.10 Mrs Smith's care journey map (Stage: *Diagnosis*)

It is worth pointing out that the user journey map can also be used to analyse a part of a patient's care journey, to understand the capability-related experience and challenges of a single activity/task of the patient within a specific scenario. Figure 5.11 presents an example to analyse an activity related to patients' transport to the GP surgery. Most of the participants chose to go to GP surgery by car instead of walking due to their limited mobility, which could reflect the condition's effect on patients' mobility, although the data was based on a small number. This example indicates the importance of increasing the utilisation of the PR service and considers the service's demand on capability, especially the mobility of patients.

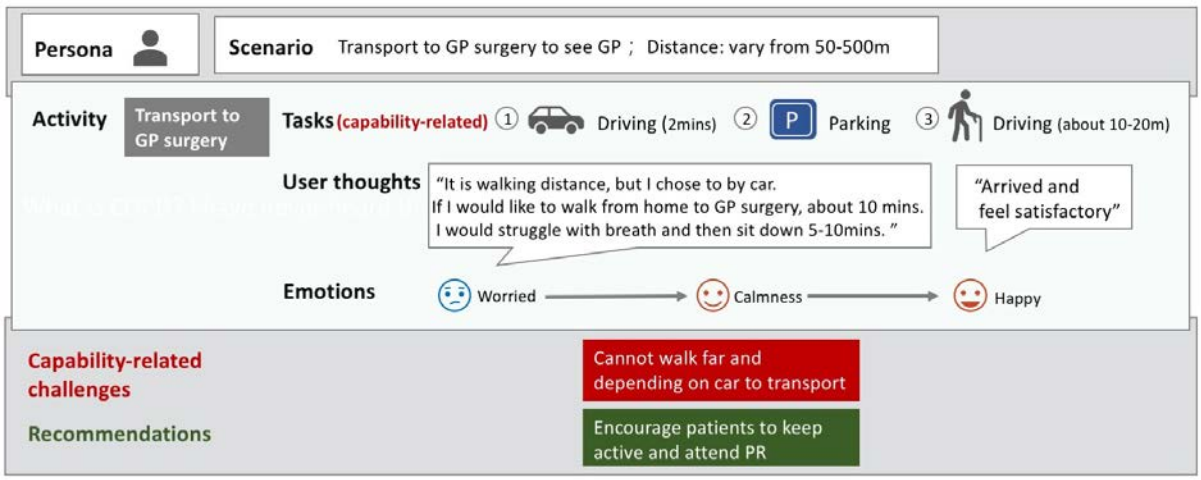


Figure 5.11 An example to analyse single activity by *user journey map*

Therefore, the principle of Inclusive Design merged into the user journey map which focuses on capabilities-related experiences and insights could be used as a coding matrix to manage and analyse the interview transcripts. A coding matrix used for understanding patients' challenges, especially capability-related challenges, is summarised in Table 5.16 based on the user journey map's elements. The last column of the table shows that the interview transcripts could be labelled by codes and used for analysis.

Table 5.16 A coding matrix for understanding patients' personal challenges

Category	Codes based on user journey map's elements	Interview transcripts
Patients' profile	Female/male, age, job, multi-morbidity(conditions)	Female, 65, retired officer, COPD & arthritis
Patients' stages	Diagnosis; Review, Referral, Assessment, PR	Diagnosis
Patients' activities/tasks of their care journey	Make an appointment, transport, consult HCPs, checked by HCPs, receive treatment, make decisions, request for help (summarised from Table 5.4)	Transport by car
Patients' experience along care journey	Patients' emotion, Patients' challenges (capability related), Patients' challenges (Non-capability related)	…
Recommendation	Patient's expectation Patients' needs (from HCPs)	…

In comparison to a *user journey map*, which focus on users, *service blueprints* focus more on employees (i.e., HCPs in this context). They are diagrams that visualise organisational processes in order to optimise how a business delivers a user experience. Generally, every *service blueprint* comprises some key elements. A template of *service blueprint* is shown in Figure 5.12. *Physical evidence* means anything that a user (customer) can see, hear, smell or touch, such as a front desk and waiting room, which is closely linked with the capability elements of Inclusive Design. *User actions* means to how the user interacts with a service, e.g., signs in and waits. *Onstage (frontstage) actions* refer to actions that occur directly in view of the user, e.g., welcome; and *backstage actions* refer to steps and activities that occur behind the scenes to support onstage happenings, e.g., triage patient. *Processes* mean the internal steps, and interactions that support the employees in delivering the service, e.g., triage patient into Dr Dan's cart.

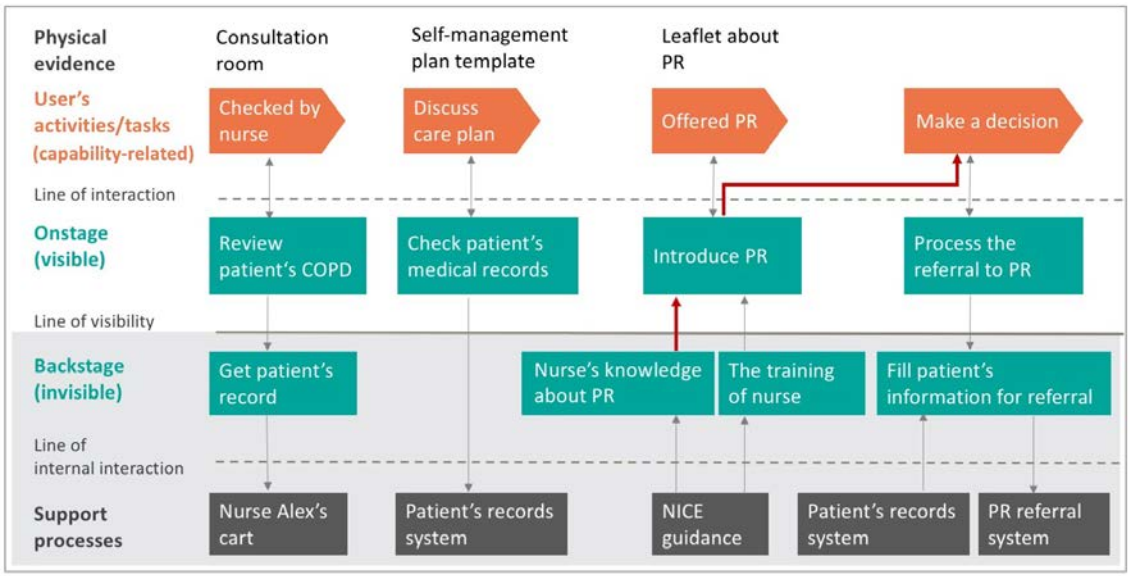


Figure 5.12 A template for service blueprint (adapted from Hegeman *et al*., 2007)

It is important to clarify that a *service blueprint* corresponds to a specific user journey and goals associated with that journey. As the journey varies in scope, there might be multiple service blueprints within different scenarios. In this case study, the *service blueprints* were mainly used to understand the interaction between HCPs and patients, i.e., the consultation process including care plan, in particular the service's demand on patients' capabilities within different scenarios. Figure 5.13 shows an example of using the service blueprint to analyse the scenario, i.e., the practice nurse selling the PR service to people with COPD. The nurses' knowledge about PR may affect the way in which they introduce PR to patients and patients' perceptions about PR (thinking capability). The internal interaction could be better analysed

by utilising the *service blueprint* and thus understand HCPs' challenges/needs as well as the potential demands on patient's capabilities.

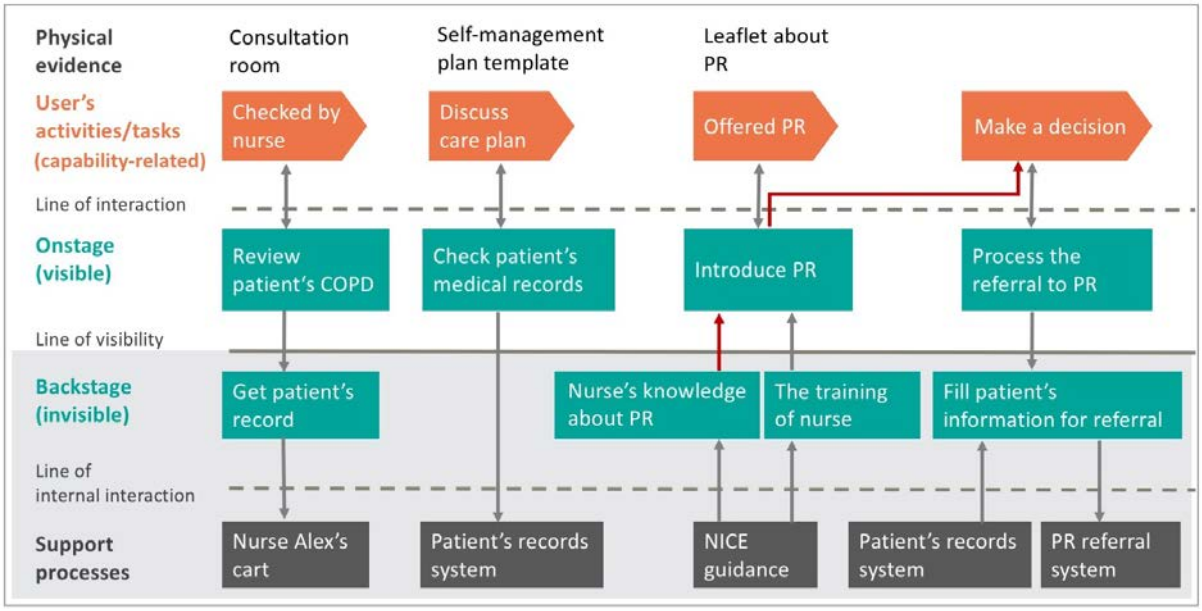


Figure 5.13 An example of using the service blueprint to analyse a scenario

Therefore, with a reference to the *service blueprint*'s elements, another coding matrix for understanding the challenges of HCPs and predicting patients' needs was created (Table 5.17).

Table 5.17 A coding matrix for understanding challenges of HCPs and the care system

Category	Codes based on service blueprint's element	Interview transcripts
Stage	Diagnosis, Review, Referral, Assessment, PR	Diagnosis
HCPs' profile	Role/position	GP
Patients' activities/tasks of their care journey	Make an appointment, transport, consult HCPs, checked by HCPs, receive treatment, make decisions, request for help (summarised from Table 5.4)	…
HCPs' activities/tasks of their care pathway)	Have an appointment, undertake consultation, refer patients, check patients' health, educate patients, offer treatment, discuss care plan, make clinical decision, selling PR, do assessment, inform patients (summarised from Table 5.1)	…
HCPs' experience along care pathway	HCPs' experience/stories, HCPs' emotion, HCPs' challenges	…
Support network	APPs; organisations' support network	…

With regard to the *experience map*, it looks at a broader context of human behaviour, which generalises the concept of user (customer)-journey maps across user types and products. An *experience map* is a visualisation of an entire end-to-end experience that a "generic" person goes through in order to accomplish a goal. It is not tied to a specific business or product, which is used for making generalisations about user experience (as opposed to a customer journey map, which is more specific). Normally, the *experience map* can be split into 4 swim lanes:

phases, actions, thoughts, and mindsets/emotions, but the category could be changed flexibly according to the targets (Nielsen Norman Group, 2016). An example of the experience map for pregnancy is described in Figure 5.14.

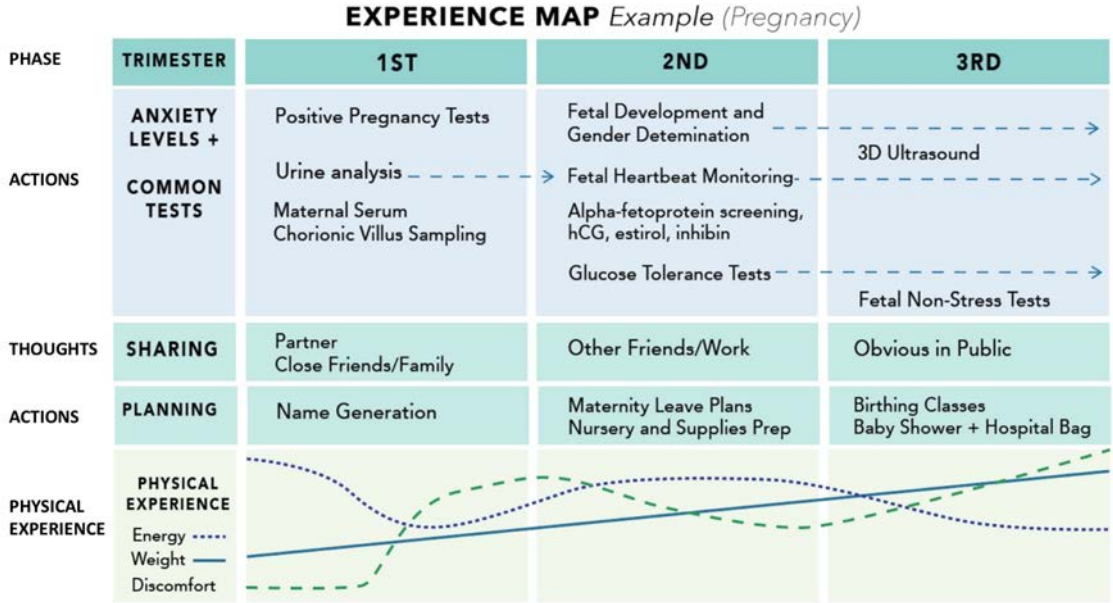


Figure 5.14 An example of experience map (Nielsen Norman Group, 2016)

In this study, the *experience map* was used to develop an ideal and inclusive process for users to experience when they access PR services. The coding matrix based on the experience map could help identify and manage codes such as key activities of patients and patient's expectations (see Table 5.18), although some codes may overlap with other coding matrices.

Table 5.18 A coding matrix for identifying codes that describe an ideal user experience

Category	Codes based on experience map's element		Interview transcripts
Stage	Diagnosis, Review, Referral, Assessment, PR		Diagnosis
Ideal care journey	Actions:	Patients' expectation	"What's COPD? I have never heard it"
		Patients' needs (from HCPs)	…
		key activities of patients	…
	Thoughts: make a decision		…
	Mindset/emotion		…

Figure 5.15 shows a skeleton to illustrate the difference between these three tools. The arrows at the top show the phases of interaction. The top half represents a description of the individual's experience, touchpoints are in the middle, and the bottom represents the service an organization provides (Kalbach, 2016). A touch point refers to any point at which users interact with the organisation that provides products or services. Generally, *customer journey maps* focus on an individual's personal experiences; *service blueprints* focus on the backstage processes, the employees' sides; and *experience maps* focus on the broad user's experience.

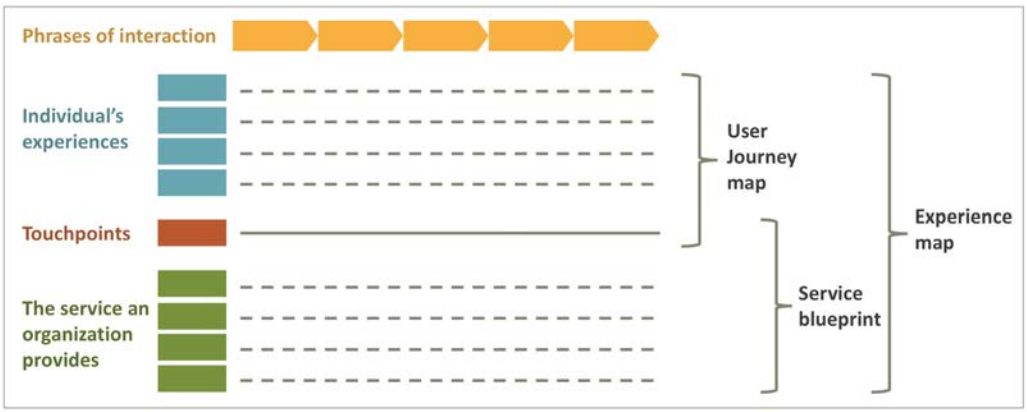


Figure 5.15 Differences among user journey map, service blueprint, and experience map

Combining the above three coding matrices, and the initial codes as well as categories, all the interview transcripts were coded in NVivo 12. Then in the *descriptive accounts* stage of framework analysis, the coded data were summarised and synthesised by refining the initial codes/categories, for example, the new code *after PR* was added, and the category barriers were merged into the code *patients' challenges (Non-capability related)* (Table 5.19). The definitions of the final version codes can be found in Appendix C16. The two previous researchers were also involved in reviewing the refining process: three random selected transcripts of HCPs and three transcripts of patients were coded by a second researcher to reduce bias and ensure the coding was reasonable. The process to *distil more abstract concepts* and the stage *explanatory accounts* were introduced in the *output of the data analysis*.

Table 5.19 The final version of category and codes of analysing interview data

Category	Codes(nodes)
Stage	COPD Diagnosis, Annual Review, PR referral, Assessment for PR, PR Programme, After PR
Profile	Patients' profile, HCPs' profile
Patients' activities/tasks of their care journey	Make an appointment, transport, consult HCPs, checked by HCPs, receive treatment, make decisions, request help (summarised from Table 5.4)
Patients' experience along care journey	Patients' emotions, Patients' challenges (capability related), Patients' challenges (Non-capability related)
HCPs' activities/tasks of their care pathway	Have an appointment, undertake consultation, refer patients, check patients' health, educate patients, offer treatment, discuss care plan, make clinical decision, sell PR, do assessment, inform patients (summarised from Table 5.1)
HCPs' experience along care pathway	HCPs' emotion, HCPs' challenges
Care related	HCPs' perceptions about PR, Patients' perceptions about PR, Patients' knowledge about COPD care, HCPs' knowledge about COPD care, Patients' education, HCPs & patients' relationship, Communication between HCPs, Communication between HCPs and patients, Factors affect uptake and attendance
Recommendation	Patient's expectation, Patients' needs (from HCPs)
Support Networks	Apps, Personal support network, Organisation support network, Information channel
Others	Motivation, Sociability, Confidence

Output of data analysis

Regarding the process of distilling more abstract concepts, there were four categories that related to identifying challenges and recommendations for patients accessing a PR service: the challenges of Patients (see Table 5.20), the challenges of HCPs (see Table 5.21), patients' expectations and patients' needs from HCP's perspectives (see Table 5.22). Specifically, the main challenges for patients accessing PR services were divided into *non-capability-related challenges* and *capability-related challenges* (Table 5.20). It is worth noting that some non-capability-related challenges may also influence patients' capability and thus affect their access to PR. For example, the patients may feel anxious and depressed if they '*have never heard the term COPD*,' and thus they may not be able to concentrate (a part of thinking capability) on expressing their needs clearly (speaking, a part of thinking capability) and looking for help.

Table 5.20 The main challenges for patients accessing PR services

Capability-related challenges	**1. Mobility**	
	Challenges	*Interpretation*
	i. Cannot get to the GP practice because of breathlessness ii. Cannot get to the assessment /PR class venue iii. Have difficulty in shuttle (walking)tests for assessment iv. Limited mobility in winter and bad weather (rain) v. Have difficulty in climbing stairs/ hills vi. Cannot walk long and need rest	i-ii: It is likely to be difficult for patients with COPD to use transport to healthcare services. iii-v: Most people with COPD have limited mobility, in particular in bad weather/seasons and on certain roads, which affects their daily activities.
	2. Other Capability (Vision, Hearing, Thinking, Reach&Dexterity)	
	Challenges	*Interpretation*
	i. The font size on inhaler's instruction is too small to read ii. Vision declined due to COPD iii. Some medication for COPD has side effects for vision iv. Have hearing problems and need to wear a hearing aid v. Language barriers vi. Other conditions such as arthritis and bad hips affect attending PR class	i: The medication's instruction needs to be well-designed to ensure patients with COPD can read it. ii-iii: The vision of patients with COPD may be affected by COPD medication. iv: Although hearing capability may not be affected by COPD, it somehow affects people's access to PR such as make a call or listen to the education session. v: Some patients need interpreters' help to access care. vii: Patients' access PR may be affected by other conditions.
Non-capability-related challenges	**3. Perception about COPD**	
	Challenges	*Interpretation*
	i. Have never heard the term COPD ii. Cannot accept the fact they have COPD	i-ii: People not familiar with COPD may feel fear and not accept that they have COPD, and this may affect their thinking capability and mental health.
	4. Care-related	
	Challenges	*Interpretation*
	i. Cannot access proper information in each stage ii. GP/nurse just helps with one thing at a time iii. The challenge of doing spirometry test iv. Have no maintenance v. Have difficulty in quitting smoking vi. Cannot commit to the PR class twice a week vii. Long waiting time to get referred viii. Long waiting time to start PR class	i: Access to proper information is the key for people to self-manage their condition. ii-iv: The challenges originate from limited consultation time and health tests. v: Some patients need support to quit smoking. vi: Some patients may need the class tailored for them. vii-viii: Patients should be offered other alternative support during the waiting time.
	5. Others	
	Challenges	*Interpretation*
	i. Nobody to speak to ii. Dependence on families/friends for transport iii. Limited financial resources (cannot afford a scooter to commute)	i: Patients need someone to talk to especially at the moment they are newly diagnosed. ii: Patients may rely on carer's help, which means their attendance is also affected by the carer's schedule. iii: Some patients may need financial support.

The main challenges for HCPs to engage patients with PR were summarised into three categories: *information, communication with patients, HCPs' professional knowledge* (Table 5.21). Some challenges of HCPs may also help identify patients' potential needs, for example, the fact that patients would like to have face-to-face communication and be better understood by HCPs could be discerned by HCPs' challenge regarding communication with patients (category 2). Overall, the potential needs of patients discerned from the interpretation of patients and HCPs' challenges were about *transport service, better guidance of using inhalers, proper information and support in different stage, tailored PR programme, and reassurance*.

Table 5.21 The main challenges for HCPs to engage patients access PR

1. Information	
Challenges	*Interpretation*
i. Delay referring patients due to lack of patients' contact information ii. No leaflets available to offer to patients iii. No up-to-date information for patients iv. No up-to-date information about referral, e.g., referral form	i-iv: The efficiency of HCPs in obtaining information including patients' information and treatment information affects how well they engage patients in attending PR.
2. Communication with patients	
Challenges	*Interpretation*
i. Referrals are not done face-to-face by physios (some situations) ii. No enough time to understand where patients are	i-ii: Face-to-face communication is vital to persuade patients to take up and attend PR.
3. HCPs' professional knowledge	
Challenges	*Interpretation*
i. Wrong diagnosis between asthma and COPD ii. The skills for selling PR	i: HCPs' knowledge about distinguishing similar conditions. ii: The skills of HCPs to encourage patients to attend PR.
4. Others	
Challenges	*Interpretation*
i. Long waiting list causes patients to lose their initiative to attend PR ii. Patients influence others' attendance	i: It is challenging to keep patients motivated to attend PR. ii: Patients' attendance is affected by other participants.

Table 5.22 summarises the patients' expectations, and their needs from HCPs' perspectives based on the interview data. The key themes of patients' needs were around *information, flexible PR programme, timely referral, reassurance and transport services*.

Table 5.22 Patients' expectations and patient's needs from HCP's perspectives

Patients' expectation	**Interpretation**
i. Have more Information about treatment ii. Offer other formats of PR programme such as TV program iii. See my GP not other GPs who do not know me iv. Have PR referral earlier v. Have someone to talk with about their conditions	i: Patients are looking for proper information at each stage. ii: Other flexible formats of the PR programme should be available for some patients. iii: Patients are looking for someone who knows them to offer treatment. iv: The earlier eligible patients attend PR, the better they can self-manage their condition. v: Patients are looking for understanding and support from HCPs, families and friends.
Patients' needs from HCP's perspectives	**Interpretation**
i. Reassurance and understanding when informed of their diagnosis ii. Attentation to psychological heath iii. Tailored PR service if possible to meet patients' needs iv. Transport help v. Referral at early stage	i-ii: Patients looking for reassurance especially when they are newly diagnosed. iii: Patients' uptake and attendance are likely to improve if the class can be tailored. iv: Some patients need transport support. v: It is essential to refer eligible patients at anthe early stage.

b) Proposing initial recommendations

In the explanatory accounts stage of framework analysis, three themes were suggested to increase patients' access to PR (Figure 5.16) through integrating the summarised patients' needs and demand as well as exclusion data (step 2, page 101-104):

i) *Reassurance*: patients should be offered an overall picture of the COPD care journey and engage in decision-making, thus giving them a sense of controlling their conditions;

ii) *Information*: proper information and reminders should be provided to patients at each stage;

iii) *Support*: flexible and timely treatment options should be offered to patients, e.g., other formats such as videos could be available for patients who are not able to get to the class (transport).

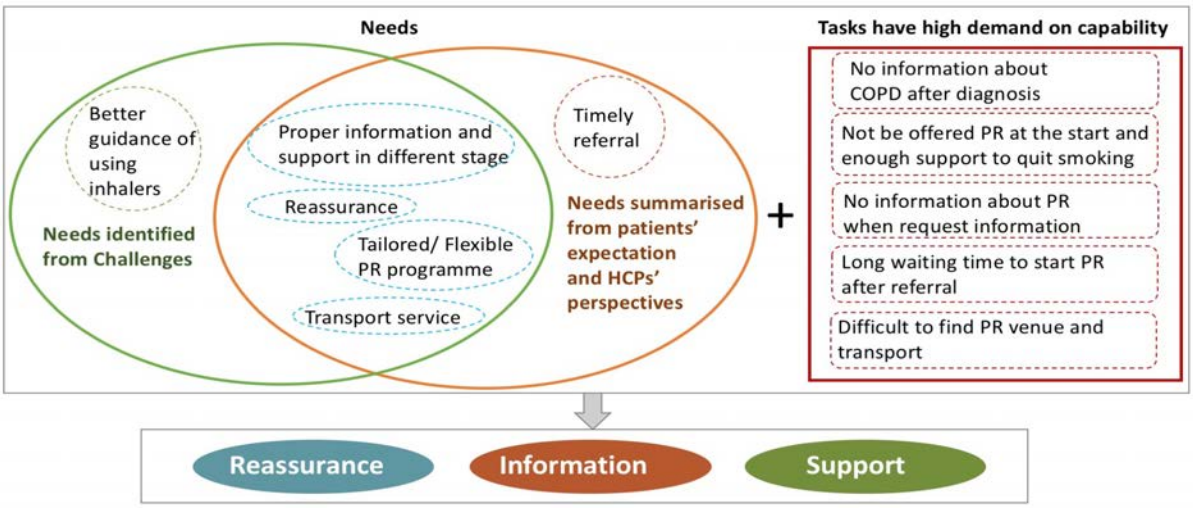


Figure 5.16 Patients' needs to better access PR

As a result, the initial recommendations, which aim to address patients' challenges and meet their needs when accessing PR were proposed, to provide patients with reassurance, information and support in different stage of their COPD care journey (Table 5.23).

Table 5.23 Initial recommendations for improving patients access to PR services

Stage	Recommendations
COPD Diagnosis	1. Reassure patients by offering them proper information to understand COPD conditions. (thinking) 2. Offer multiple treatment options to patients to make them feel supported, in particular, advertising PR to patients.
Regular review	1. Remind patients to have their regular reviews for COPD. (thinking) 2. Provide patients with information and support after review if needed.
Referral to PR	1. Offer patients PR and provide contact information to patients for them to self-check. (thinking) 2. Send invitation for PR to patients in a timely manner.
Assessment to PR	1. Provide patients with clear navigation instructions to get to the assessment venue. (vision) 2. Remind patients to bring documents especial medication list when coming for assessment. (thinking) 3. Sell PR to patients and try to meet patients' needs.
PR	1. Providing patients with transportation if they have difficulty in getting to PR. (mobility) 2. Tailor the PR class to patients if needed. (Reach & Dexterity, mobility) 3. Pay attention to patients who have a hearing impairment or declined thinking. (hearing) 4. Encourage patients to do exercises at home. 5. Offer support if patients need it.

c) Answering research questions (CS2-RQ3)

The purpose of this step was to answer the research question: *How can we use the principle of Inclusive Design to improve people's access along their PR journey* (CS2-RQ3)? The principle of Inclusive Design in this context ensured the capability demands made on patients when they access PR service do not exceed their capabilities to respond, which could be interpreted as identifying patients' capability-related challenges and trying to minimise these challenges so as to improve people's access to PR services.

In this case study, patients' capability-related challenges were identified in two ways. Firstly, the key elements of service design tools were drawn on (i.e., *customer journey map, service blueprint* and *experience map*) and merged with the capability-related elements of Inclusive Design to gather insight into the capability-related experiences of patients from both patients' and HCPs' perspectives. Secondly, similar to case study 1, the PR service's demands on patients' capability were revealed by task analysis and the Inclusive Design tool, Exclusion Calculator. The tasks that placed a higher demand on patients indicated the potential capability-related challenges and needs of patients. In addition, the exclusion number could give a clue about the service's exclusion rate and raise the level of awareness of service providers to improve the service.

To sum up, there are two ways to apply Inclusive Design to improve people's accessing PR services: i) the focus of Inclusive Design could merge with service design tools to understand patients' capability-related experiences and challenges; ii) the Inclusive Design tools could measure capability demand on patients' capabilities along their care journey and the service exclusion.

5.2.1.4 Step 4: Propose recommendations

Step 4 contains three parts: a) Propose recommendations: the initial recommendations were integrated into a COPD care reminder (called *Your COPD Care Reminder*), which aimed to help patients understand their needs and manage their COPD care; b) Refine recommendations: "*Your COPD Care Reminder*" (Appendix C20) was refined with focus groups with patients and a survey with HCPs; c) Answering research questions (CS2-RQ4), *i.e., Is Inclusive Design useful to improve the healthcare experience of people with COPD in the community?* . The details were shown below:

a) Propose recommendations

The initial recommendations were integrated into the "*Your COPD Care Reminder*" that helps

patients self-manage their conditions (see an example in Figure 5.17). Specifically, it contains 7 cards, 5 scenarios and a set of questions that encourages patients to consider their potential needs along their COPD care journey, in particular, those needs that were caused by their reduced capabilities when trying to access PR. Figure 5.17 shows the card in the PR programme scenario, where some key issues relating to patients' capabilities were asked to inspire patients to self-check their situations.

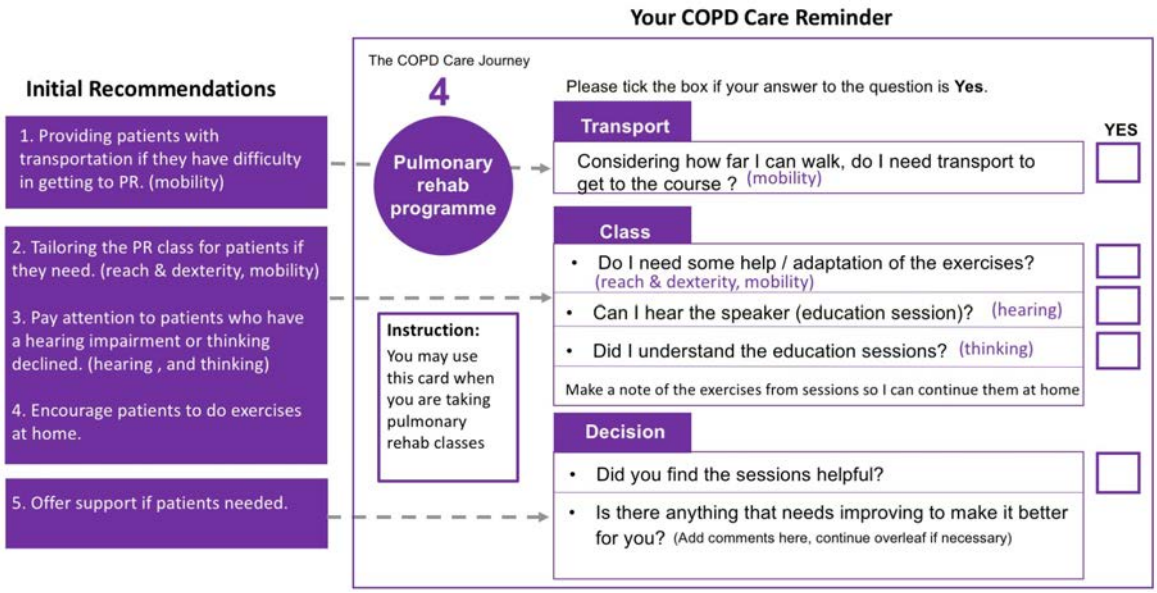


Figure 5.17 The PR programme scenario of the COPD care reminder

b) Refine recommendations

Refining recommendations contained three parts: *Design, Comments and responses for refinement*.

Design

Focus groups with patients and a face-to-face survey with HCPs were used to refine the "*Your COPD Care Reminder*". Specifically, a focus group schedule with patients was developed and piloted with two volunteers to ensure questions were neutral and useful to improve "*Your COPD Care Reminder*", and the time for the focus group was sufficient. Specifically, the focus group schedule (see Appendix C18) was designed in three parts:

i) *Introduction* was mainly to greet the participants, sign the consent form and share the ground rules of the focus group;

ii) *Body* was aimed to check the recommendations in the COPD care reminder.

iii) *Closing* expressed gratitude and checked whether participants had any questions.

The survey with HCPs was designed to be completed within 10 minutes. The questions were mainly to check the rationale of the recommendations and gather HCPs' comments to improve

the *COPD care reminder* (see Appendix C19).

In total, three focus groups with patients and a survey with HCPs were conducted:
i) Two focus groups were conducted with patients from *Breathe Easy Cambridge Support Group* to obtain the patients' views of the proposed COPD care reminder on 19th September and 17th October 2017 respectively.

ii) A further face-to-face survey with HCPs (including PR provider managers and physiotherapists) was conducted to obtain the views of HCPs on the proposed COPD care reminder in the meeting room of CUH on 11th January 2018.

iii) After the COPD care reminder was refined based on the comments of the two focus groups and survey, one more focus group with patients from the *Breathe Easy Cambridge Support Group* was organised to further check the refinements on 18th May 2018.

The focus group invitations package was given to the patients one month before the discussion. It contained a lay research summary (see Appendix C5) and a patients' participant information sheet for the focus group (see Appendix C17). Participants were also given enough time to read the invitation package again and sign the consent form (Appendix C15) before the discussion. The survey with HCPs was disseminated after the East of England PR meeting in CUH. The participants filled the survey anonymously.

Comments and responses for refinements

The comments collected from the focus groups and survey were summarised, and revisions were made accordingly. The details are presented below:
i) Four patients participated in the first focus group and five patients in the second, and all of them gave very helpful comments to improve the COPD reminder.
For example, the initial COPD care reminder (V0.1) only had five scenarios which were based on the five main stages of the COPD primary care pathway. However, during the first focus group meeting, patients raised questions about after PR, "what happens next? What is the future? I have gone through all the five stages of COPD." As a consequence, another scenario, i.e., *6. Next* has been added to provide patients with more information and support since proper access information can reassure patients, which may influence patients' concentration. The main comments and corresponding responses are outlined in Table 5.24.

Table 5.24 Comments from patients and corresponding responses

No	Comments	Response
1	"2 years after PR, what things we can do after PR?" "what happens next? What is the future? I have gone through all the five stages of COPD".	A scenario, i.e., 6. Next has been added to provide patients with more information and support. *(Thinking- concentration)*
2	In the *2. Referral to PR* scenario, more statement can add to encourage patients to attend PR.	A statement "Results show that this is always beneficial, and you should accept the offer" was added.
3	In the 3. Assessment for PR scenario, I had forgotten to bring my medication when I went to the assessment.	A question that reminds patients to bring medication was added "Have I brought a list of my medication?" *(Thinking- memory)*
4	In *4. PR programme*, the question, "How far can I walk? Do I need transport support?" needs to be rephrased as people may not know how far they can walk.	The question has been rephrased to "Considering how far I can walk, do I need transport to get to the course?"
5	In *5. Regular review*, a statement that can remind people to record their review data would be helpful.	A statement "*Record date here*" was added after the question "Do I know when my regular reviews for my COPD are due?". *(Thinking- memory)*
6	"It would be good for the GP or nurse to give you something to read, you have a backup to know what to do.	GP practices will be one of the main dissemination venues for the COPD care reminder.
7	It would be good if we could click the box to mark that we have checked that question.	A statement "Please tick the box if your answer to the question is YES" was added at the beginning of every scenario.
8	It would be helpful to patients who are newly diagnosed with COPD, and for me, who was diagnosed five years ago, to remind me of some activities.	The purpose of this COPD care reminder is to help patients especially newly-diagnosed patients to self-manage their condition and avoid exacerbation to hospital.
9	The space for filling out some questions does not seem enough and may use the next page.	A statement "Add comments here, continue overleaf if necessary" was added.

ii) 10 HCPs participated the survey and all of them thought the reminder was easy to understand, and most of them (8/10) agreed that it is good to use patients' care journey to remind them manage their care. The critical feedbacks were around the contents(elements) that should be included in the reminder and the effectiveness of using the "*Your COPD Care Reminder*". For example, one HCP mentioned, "a reminder that ongoing exercise after PR is essential", which is a very useful comment and has been added in the *4. PR programme*. The detailed comments and related responses were summarised in Table 5.25.

Table 5.25 Comments from HCPs and related responses

Participants	Comments	Response
H2	A reminder/prompt that ongoing exercise is essential.	A statement has been added in *4. PR programme* "make a note of the exercises from sessions so that I can continue them at home." *(Thinking- memory)*
H3	Carers' responsibilities	Not applicable with only focus on patients.
H4	More information on exacerbations (rescue pack) and who to contact and what to do	Patients are recommended to request the information about rescue pack in *1. COPD diagnosis* and more contact information in *2. Referral to PR*.
H7	Use with BLF passport during the discharge	The dissemination process will cooperate with BLF.
H8	- Smoking cessation should be emphasised - More information about BLF	- A reminder about considering smoking's side effect has been mentioned in *1. COPD diagnosis* - The website link of BLF is provided *in 6. Next?*
H9	Perhaps other avenues to access information to promote self-management, not just relying on the GP	The COPD reminder will be in electronic and paper format and disseminated through as many channels as possible.

iii) The refined "*Your COPD Care Reminder*" was further checked through a focus group with eight patients in the *Breathe Easy Cambridge Support Group*. It received positive feedback from patients who thought it was a convenient and portable tool for them to know their situation and manage their COPD. In particular, a patient who was newly diagnosed with COPD and had not been referred to PR spoke highly of the reminder. Meanwhile, some useful comments were collected, for example, introducing the *Breathe Easy Support Group* to patients in scenario *6. Next* to help patients find groups and support.

Overall, an approach that considered patients' capability needs in different care scenarios was developed, which contained a general map and key points of patients' COPD care journey. The reminder could also be used as an interactive tool to help HCPs better understand patients' needs, especially to understand patients' capability-related needs for accessing PR and self-managing their COPD conditions. Besides the contents of the "*Your COPD care reminder*", the principle of Inclusive Design was applied in deciding the printing size of the COPD care reminder, i.e., three printing sizes, A4, A5, A6 were evaluated by patients to ensure the size was inclusive. The A5 size was selected as the primary dissemination size, and A4 size was also available for someone who preferred a larger size. All the versions of the "*Your COPD care reminder*" can be seen in Appendix 25.

c) Answering research questions (CS2-RQ4)

The purpose of proposing recommendations to meet patients' expectations and needs was to gather more evidence to answer the research question, *Is Inclusive Design useful to improve the healthcare experience of people with COPD in the community (CS2-RQ4)?*

There are mainly four aspects to show that Inclusive Design is useful to improve the healthcare experience of people with COPD (accessing PR service in this context) in the community:
i) The Inclusive Design approach requires an understanding of patients' tasks when they access PR services, in particular, the tasks that place demands on patients' capabilities, which is the basis upon which to improve patients' experience in accessing the care (see step 1 for details).

ii) Inclusive Design could help identify patients' challenges in accessing PR services along their care journeys by estimating the demand and calculating the service's exclusion. In most cases, the challenges of patients could reflect their potential needs, which are the main factors affecting patients' healthcare experiences (see step 2 for details).

iii) The principle of Inclusive Design could be merged into some tools of service design to gather insights into patients' capability-related experiences. Generally, the ultimate goal of

service design tools (i.e., *user journey map* and *service blueprint*) is to understand users' experience and improve the service to achieve "business success", which matches the target of Inclusive Design's application in the business area. However, currently, the service design tools are not focused on patients' capability-related experience specifically. Therefore, the principle of Inclusive Design combined with the elements of service design tools could be useful in understanding and improving patients' capability-related experience (see step 3 for details).

iv) Inclusive Design is helpful to develop an ideal experience map for patients to self-manage their COPD and access PR services. The "*Your COPD Care Reminder*" describes an experience map for patients to better access PR services. The capability-related needs of patients were considered in proposing the COPD care reminder so as to create an inclusive experience for them. The positive feedback validated the significance of this COPD care reminder (see step 4 for details).

Overall, the answer to the research question (CS2-RQ4) is that Inclusive Design is useful to improve the healthcare experience of people with COPD in the community.

After introducing the study procedures above (Section 5.2.1), it is necessary to present *sampling and recruitment, study setting, patient and public involvement, research bias, and ethics and dissemination*, which were essential to carry out this case study. The details are provided in the following sections from 5.2.2 to 5.2.6.

5.2.2 Sampling and recruitment

Well-planned sampling and recruitment were important to carry out the research with limited time and resources. The *sampling sites, eligibility criteria, size of the sample, sampling technique, sample identification* are considered and described below:

Sampling sites

Sampling was carried out in a single region, the East of England in the UK, that covered both urban and rural areas. The sites available to the researchers were limited; however, sites in both urban and rural settings were included to encourage a broad selection of professionals and patients to enrol in the study.

Eligibility Criteria

i) HCPs who can refer to PR programmes from their primary care annual review, physiotherapists who provide PR, PR service managers, and the CCG strategy managers in

Cambridgeshire and Peterborough.

ii) People resident in the East of England, aged 18 or over, with a diagnosis of COPD, free from exacerbation or hospitalisation within the preceding four weeks, eligible for PR as defined by the guideline recommendations and able to read/write in English.

Size of the sample

Warren (2002) suggested that the minimum number of interviews needs to be between twenty and thirty for an interview-based qualitative study to be published. Mason reported that the interview number range was 1 to 95 (with a mean of 31 and a median of 28) for interview-based qualitative studies in doctoral theses (Mason, 2010). Adler also advised the best number of people for qualitative research is between a dozen and 60, with 30 being the mean (Baker and Edwards, 2012). The size of the sample in this study was consistent with these recommendations and the details are shown in Table 5.26. The size of the sub-groups was adjusted as necessary to reach data saturation to ensure the validity of the results.

Table 5.26 The size of sample

Category	Healthcare professionals (HCPs)	Patients with COPD	Total
(Step 1: Mapping pathway) Semi-structured interview	6 HCPs (including GPs, practice nurses, or physiotherapists), 1-2 service managers, and 1-2 commissioners. (face-to-face or by telephone)	11-17 patients with COPD including those accepted a PR offer, declined a PR offer, and never referred. (face-to-face or by telephone)	8-10 HCPs 11-17 patients
(Step 4: Propose recommendations) Refinement	Face-to-face survey with about 10-15 HCPs (physiotherapists and service managers	4-8 patients × 2-3 groups who attend the Breathe Easy Support group	10-15 HCPs 8-24 patients

Sampling technique

Data saturation refers to a process of data collection whereby no substantial new insights are generated. This sampling strategy was used to gather data in Cambridgeshire and Peterborough. Sampling was informed by the interview results to represent a range of care pathways/journeys and their experiences along the care pathways/journeys. A *stakeholder map* was used to help identify a representative sample and gather adequate data. The detailed plan is shown in Tables 5.27 and 5.28 (where *n* refers to the number of people):

Table 5.27 Recruitment plan for healthcare professionals

Healthcare professionals' role	Understanding of PR pathway
GPs/ Practice nurses (n=6)	Familiar with the process of diagnosis, annual review, and referral
Physiotherapists (n=4-6)	Familiar with the process of referral, assessment for PR, PR programme, and annual review
PR service manager (n=1-2)	Familiar with the whole PR pathway process and having connections with other professionals
Commissioners & manager (n=1-2)	Familiar with the process of designing or supporting the COPD care pathway

Table 5.28 Recruitment plan for patients

	PR programme	Age group	Capability
People with COPD	Accepted PR offer (n=5-7) Declined PR offer (n=3-5) Never referred (n=3-5)	16-49 50-64 65-74 (n≥5) 75+ (n≥2)	Hearing, Vision, Mobility, Dexterity, Reach and Stretch, Communication, Thinking. Ensure a full range of capability loss is covered by the samples

Sample identification

Access methods were discussed with Clinical Research Network (CRN) Eastern.

HCPs were identified by:

i) working with CRN Eastern locality managers to access HCPs;

ii) accessing HCPs through visiting or emailing GP Practices;

iii) accessing PR providers through the East of England (EoE) PR network.

In terms of identifying patients with COPD:

i) people who accepted a PR offer were identified through PR provider registers.

ii) people who declined a PR offer were challenging to engage. HCPs and PR providers were asked to identify people they knew, and the British Lung Foundation was involved to engage this group, e.g., through telephone interviews/ home visits, or interviews while people visited their practice for an annual review.

iii) people who had never been referred to PR were identified through COPD registers in participating GP practices. One GP practice in a city centre and another in a rural area were sampled respectively.

5.2.3 Study setting

In terms of study setting, interviews with HCPs took place at their place of work or other NHS premises by arrangement. Interviews with patients took place on community premises where PR classes were conducted, where *Breathe Easy Support Group* meetings were held or at a location of choice (i.e., the Engineering Department of University of Cambridge or their home with someone accompanying the researcher or in a coffee shop). Interviews that were conducted in a PR setting were on a one-to-one basis to minimise any bias or any external influence.

Overall, it was worth being pragmatic about the timing, location and other environmental factors; however, the analysis formally reflected on the influence of contextual factors on the interpretation of the results.

5.2.4 Patient and Public Involvement (PPI)

The aim of PPI activities was to ensure that the study gathered patients, accompanying carers and healthcare professionals (HCPs) together to deliver the research collaboratively so that it comprehensively addressed patient needs. Patients' enthusiasm was encouraged, and their continuing contributions were welcomed.

Five patients with COPD contributed to the research questions, aim, participant sheets, interview schedule, consent forms and the plain English summary. Several discussions were held with three physiotherapists who provided clinicians' perspectives on the research questions, aim, participant sheets, interview schedule and consent forms for HCPs. The lay summary and interview materials (participant information sheets) were reviewed by nine members of the PPI panel, Cambridge University Hospitals. They confirmed the language used was understandable and provided useful comments to refine the research.

The study results were disseminated to study participants by post or email based on their preferences.

5.2.5 Research bias

To reduce the chances of acquiescence bias when designing research, the interviews and focus groups were carefully designed and reviewed by experts including healthcare professionals as well as researchers, and patients to ensure the questions were short and clear, and the answer choices were short and concise. The research protocol was reviewed by the Research Advisory Committee (RAC) of Cambridge University Hospitals and advice was received from the members of the Patient and Public Involvement (PPI) panel, Cambridge University Hospitals (CUH, an NHS Foundation Trust) before being sent to the ethics committee. In the steps of refining the recommendation, the acquiescence bias may also appear as the HCPs and patients may assume the research as an expert. An anonymous survey with HCPs may allow them to show their ideas freely. Focus groups with the same people twice may also help to notice if there is an acquiescence bias, although it could not be avoided.

To reduce the risk of confirmation bias during data analysis, the work was supervised by a senior researcher of the EDC. A second researcher from CUH independently analysed some of the data at each stage of the analysis. The primary and secondary analysts compared results and resolved any discrepancies. Should any discrepancies not have been resolved, the supervising senior researcher would have played the role of adjudicator .

5.2.6 Ethics and dissemination

5.2.6.1 Assessment and management of risk

In order to manage the risk of patients being vulnerable due to age/frailty, they were identified via GP practices or PR services to whom they were known and who could ensure participants were aware of their diagnosis of COPD prior to the researcher approaching them. Sources of support were identified to whom participants could be directed.

If there was a concern about a person's health or safety the researcher could contact the relevant GP; however, as this meant breaking confidentiality it would only have been done if the person had clearly been at risk. When making appointments for patients to attend research activities, it was ensured that the time and location were acceptable to the participant.

It was recognised that interviews may involve discussion of sensitive topics regarding the patients' health, lifestyle or quality of life. To address this:
i) All study materials, including interview questions, were developed in collaboration with a patient and public involvement group to ensure topics were addressed in a sensitive way.
ii) Participants were directed to sources of support and information.

5.2.6.2 Data protection and patient confidentiality

The Patient Information Sheet explained how the data would be collected and how it was stored.

The study complied with the Data Protection Act, which requires data to be anonymised as soon as it is practical to do so. Participants' anonymity was maintained by the researcher. Staff seeking consent asked patients only for personal data that confirmed their eligibility for the study and at no point did the study staff have access to patients' medical records.

On entering the study, participants were assigned an ID. Participant names were only identifiable on a cross-referenced list of IDs and names, which was stored in a locked filing cabinet on Trust premises. When recordings of interviews or focus groups were transcribed, only the ID was used as an identifier.

Data collected were entered onto secure computers in the Engineering Design Centre (EDC) at the University of Cambridge and were only accessible to the study team. Paper documents were stored in a locked cupboard in the EDC and were only accessible to the study team.

All electronic files were password protected and access restricted to the study team. Participants were identified only by a participant ID number on an electronic database. The name and any other identifying details were not included in any study data electronic file. Data sharing, and storage met the requirements of the National Institute of Health Research. Data was securely stored in the University of Cambridge Research Repository.

5.2.6.3 Ethical approval

This case study research was ethically reviewed and approved by the Cambridge Central Research Ethics Committee. The study' REC reference number is 17/EE/0136. It was one of the two work packages that aim to increase the number of eligible people who take up pulmonary rehabilitation (PR). Work package 1 which used an Inclusive Design approach was presented above, and work package 2 was to develop a toolkit to increase referral to and uptake of PR in primary care. The work package 1 was designed and carried out by the researcher as part of the PhD research projects, and the output of work package 1 fed into work package 2 for the toolkit development.

5.2.6.4 Dissemination

The research output will share with the British Lung Foundation (BLF), who have a track record of disseminating innovation through patient networks, publications, online information, service development and HCP engagement. Academic papers will be published in peer-reviewed journals compliant with policy on open access. Presentations will be given at regional, national and international academic and professional conferences, e.g., East Anglian Thoracic Society, British Thoracic Society and European Respiratory Society.

5.3 Discussion

Case study 2 focused on how the principle of Inclusive Design can apply to healthcare services, in comparison to case study 1 which mainly investigated whether Inclusive Design could be applied to healthcare services. At the beginning of the discussion, it is necessary to review the principle of Inclusive Design in this research, which aims to ensure that the demands made on individuals in a given environment do not exceed their capability to respond and thus make the product or service accessible to as many people as possible. Corresponding to this case study context, Inclusive Design was used to estimate the current PR services' demands on patients' capabilities, identify patients' challenges of accessing PR services, and thus propose recommendations to improve patients' experience and the number of patients to access PR

services. Figure 5.18 presents a summary of how Inclusive Design was used in this case study to improve patients access to PR services.

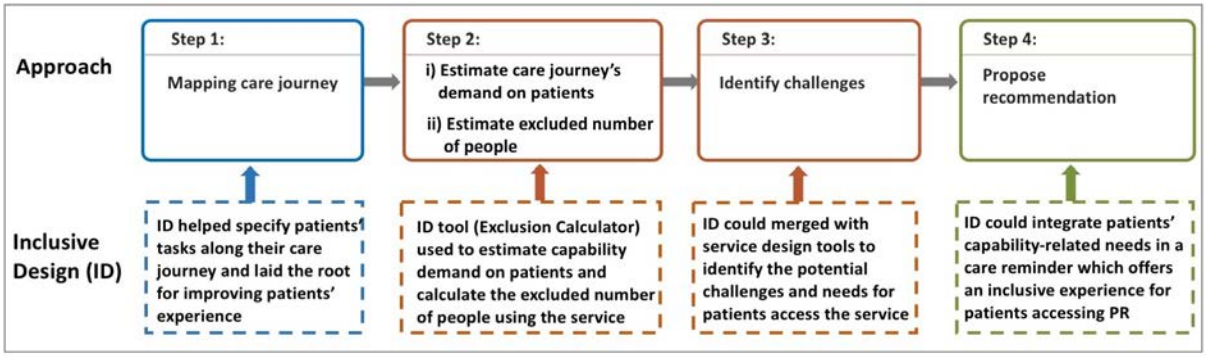


Figure 5.18 A summary of applying Inclusive Design in case study 2

Firstly, Inclusive Design could guide patients' tasks along with their care journey and lay the foundation for improving patients' experiences. Applying the Inclusive Design approach to improving the PR service requires a clear picture of how the PR service is delivered and how patients access the current service system. The demand measure scale of the Exclusion Calculator (an Inclusive Design tool, see Appendix B4) could help to direct how precisely we should specify patients' tasks along with their care journey and make it ready for estimation. It should emphasise that in contrast to using a product, which is easier to predict, how patients access a care service is much more diverse and unpredictable. Hence, it is vital to select typical tasks that patients are likely to go through, for example, the task, i.e., transport is essential and may be difficult for patients due to their limited mobility.

Secondly, similar to the case study 1, Inclusive Design together with its "aided tools" can estimate services' demands on patients and the service's exclusion. Specifically, two "aided tools" of Inclusive Design, i.e., *personas* and *scenarios* were used to define the scope for estimation. Two points require attention when creating personas and scenarios: i) The prototype of the persona should have experienced all the stages of the service to ensure coverage of more details of the care journeys if only creating one persona; ii) Some stories and experiences from other similar patients could be used to complement the scenario in order to identify more potential challenges of patients. Based on the defined scope, the demand of every task on patients could be assessed through the use of pre-defined scales. Also, the service's exclusion was estimated based on the available capability data of the British population, in particular, people with COPD within that population database were filtered and used for calculation. The exclusion number of every task could imply the most challenging task along patients' care journey and inform recommendations. To summarise, Inclusive Design tools are

useful to estimate the services' demands on patients' capabilities and calculate the service's exclusion, although the exclusion number is restricted to the population database.

Thirdly, the principle of Inclusive Design could merge with service design tools to identify the potential challenges and needs of patients accessing the service. As discussed in the literature review of Chapter 2, an intangible healthcare service is different from tangible medical products, and therefore it is pragmatic to draw on service design tools to better understand users' experiences. Specifically, Inclusive Design's principles were integrated into three service design tools, i.e., *user journey map*, *service blueprint*, *user experience map* to understand and improve patients' experiences of accessing PR from different perspectives. For example, the elements of the user journey map were tailored to focus on patients' capability-related experience and insights (Figure 5.19).

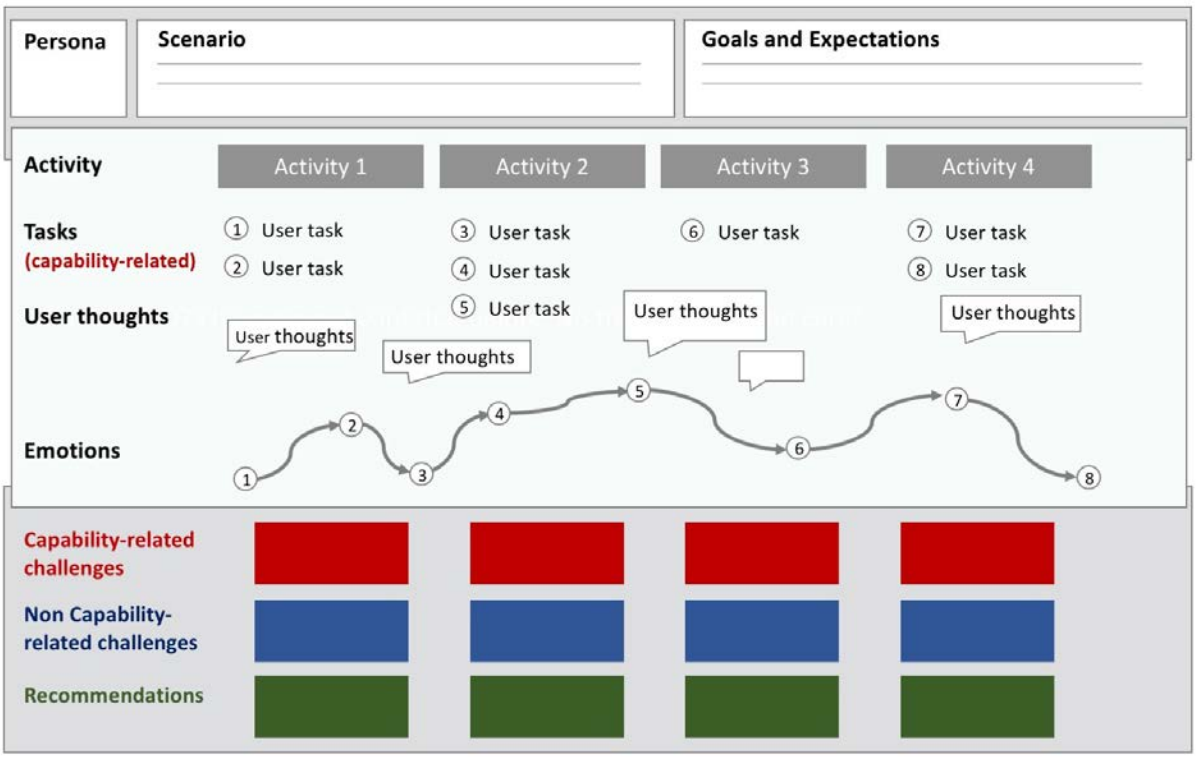


Figure 5.19 The template of inclusive user journey map

Fourthly, Inclusive Design could help address patients' capability-related needs along their care journey and thus offer an inclusive experience for patients accessing PR. A couple of questions within "*Your COPD Care Reminder*" were designed to remind patients to consider whether their capabilities meet the demand of some tasks along their care journeys in different scenarios. For example, in scenario *4. Pulmonary rehab programme* (see Figure 5.17), patients are required to think of a series of questions about their capability to attend class. The question

"*Can I hear the speaker?*" relates to patients' hearing. As a result, patients could have a better understanding about their situation and request more help if needed, which could also give them a feeling of control over their condition. In this sense, Inclusive Design could improve patients' experience in accessing PR services.

5.4 Summary

In this case study, the principle of Inclusive Design was further applied to understand a community-based healthcare service, i.e., pulmonary rehabilitation (PR) for patients with COPD. Interviews with different HCPs and patients were conducted to understand the patients' journeys and challenges in accessing the PR service. The accessibility of the PR service was evaluated through *task analysis* and *Exclusion Calculator*. The tasks that place a higher demand on patients' capabilities were identified, and the proportion of the British population and COPD patients who potentially excluded was estimated respectively. A framework analysis was used to guide the analysis of the interview data, and the principle of Inclusive Design combined some service design tools were applied to identify challenges and patients' potential needs. Finally, "Your COPD care reminder", an approach aiming to help patients better access PR service and self-manage COPD conditions, was proposed.

As for the limitations of conducting this case study, the patients that were involved in interviews were not representative of all patients, since for example, it was proved to be difficult to recruit disabled patients and patients who with severe COPD. Therefore, some capability-related needs for these patient categories might not be covered. Meanwhile, the number of interviews was relatively small due to time constraints and difficulty in recruitment. Also, the population database used for estimating excluded COPD patients was limited to the data from Disability Follow-up to the Family Resources Survey in 1997, although it remains the most holistic source of data. A survey that measures the capability of patients with COPD could be done in the future to update the exclusion number.

Overall, this case study has further demonstrated that the application of Inclusive Design to health services is possible and the tools applied can make a useful contribution to understanding service provision and hence service improvement. Chapter 6 will describe more discussions about an inclusive approach to health service design.

6 Reflections on the Inclusive Approach to Healthcare Service Design

This chapter presents an Inclusive Approach to improve people's experiences of accessing healthcare services, which draws together the results from literature review and two case studies, and answers the sub-research question 5, i.e., *What are the advantages and limitations of Inclusive Design as a means of improving people's access to healthcare services in the community*? Future work should investigate the wider application of this approach, dissemination methods and its testing in the healthcare industry.

6.1 An inclusive approach to healthcare service design

Inclusive Design has been widely used to the accessibility of buildings and public transport, as well as consumer products, but when applied to services, its characteristics would be different and need further exploration. This research focuses on applying Inclusive Design to healthcare services for medical conditions. The research process of the two case studies and summarised inclusive approach could offer healthcare researchers and providers a supplemental way of looking at people's capability-related needs when accessing healthcare services.

6.1.1 Overview

Figure 6.1 presents an overall picture of using an inclusive approach to community-based healthcare service design. It is neither a novice guide to healthcare improvements, nor a replacement for existing healthcare improvement approaches. It is an inclusive approach integrating tools and specific steps to facilitate the understanding of patients' capability-related needs both for the recipients of care and for the providers of care, with a view to improving healthcare services.

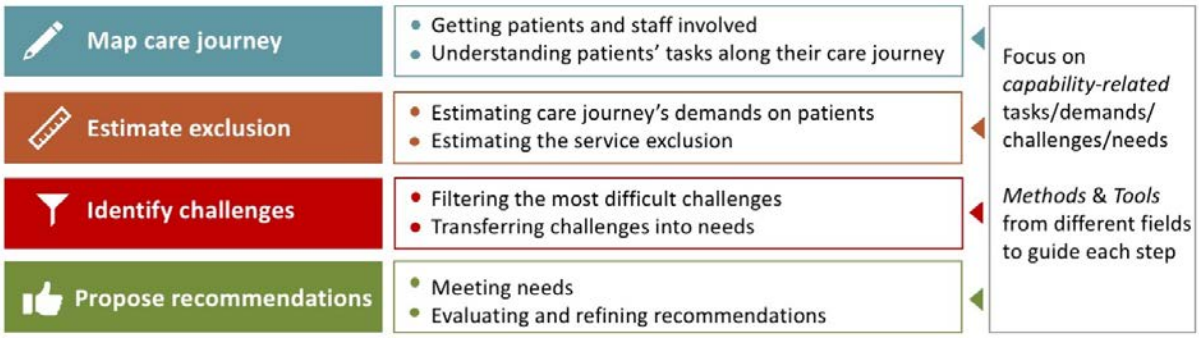


Figure 6.1 Overall picture of an inclusive approach to healthcare service design

Specifically, this inclusive approach to healthcare service design contains four steps which are outlined below.

Step 1 *map care journey* relates to getting patients and staff (HCPs) involved in sharing their experiences about delivering and receiving the current healthcare service respectively and thus understanding patients' tasks, especially capability-related tasks along their care journeys. The relevant methods and tools include data collection methods such as *interviews* and *surveys*, and tools such as the *stakeholder map* which can help sample the participants for data collection.

Step 2 *estimate exclusion* contains two parts: one is estimating the healthcare service's demands on patients' capabilities; the other is estimating the service's exclusion. The Inclusive Design tool, i.e., *Exclusion Calculator*, plays two roles in this step: i) the pre-defined scales within the tool are the standards to estimate the service's demand on patients; ii) the database of the British population's capabilities within the tool can be used to estimate the service's exclusion based on the rated demand scales. It is worth noting that the database within the *Exclusion Calculator* can be adjusted depending on the requirement. The current population database can be filtered to specific groups (e.g., people with COPD) or changed to other available databases to estimate the service exclusion. Also, two "aided tools" for Inclusive Design, i.e., the *persona* and *scenario,* are useful in defining the scope for estimate exclusion.

Step 3 *identify challenges* is achieved in two ways: one is by consulting the exclusion data in step 2, and the other is by further analysing the data in step 1 which could extract the challenges and needs of patients. Regarding the tools of this step, the principles of Inclusive Design can be merged into service design tools and used to discover patients' potential challenges. The *user journey map* focuses on understanding a single patient's capability-related experiences and insights, the *service blueprint* focuses on HCPs' experiences and thus predicts patients' needs, and the *experience map* focuses on the broader patients' experiences. The identified patients' challenges can be transferred into patients' potential needs and can be useful in proposing recommendations in step 4.

Step 4 *propose recommendations* to meet patients' needs especially capability-related needs. The recommendations could be validated and refined together with patients and HCPs through interviews, focus groups or surveys. These recommendations could be designed in different formats for patients, HCPs and healthcare providers depending on use or requirements, e.g., "*Your COPD Care Reminder*" (from the second case study) can not only acts as a reminder to patients, but also as an interactive tool for patients to actively communicate with HCPs. In addition, it is crucial to implement these recommendations to alter existing healthcare service

routines and test whether the new situation has improved the services' access if possible. Service providers and commissioners would be in charge to promote the implementation of recommendations.

Table 6.1 summarises the main methods and tools that can be used in each step of the inclusive approach. As stated earlier in this section, the aim of this Inclusive Approach is not to be a new guide or replacement approach to improving healthcare. In fact, it is an approach that integrates the existing tools and methods to understand capability-related tasks, demands, challenges and needs of patients in accessing healthcare services. Some other methods and tools which are not listed here can also be used in this approach. For example, *the diary study*, a research method for collecting qualitative data about user behaviours, activities, and experiences over time, can be used to understand patients' care journeys and specific capability-related tasks in the *map care journey*.

Table 6.1 Methods and tools used in the inclusive approach to healthcare service design

STEP	Map care journey	Estimate exclusion	Identify challenges	Propose recommendations
Methods &Tools	Interview Survey Secondary data collection Stakeholder map	Task analysis Persona Scenario Exclusion Calculator	User journey map Service blueprints Experience map	Survey Focus group Interview

In terms of who would actually undertake the recommended analysis, the following three categories people should be considered. Firstly, care providers, HCPs, healthcare researchers should be involved as they are familiar with healthcare services system. Inclusive Design experts or people who have some design knowledge should also be invited into the team. It is also vital to involve patients who are the service users into the analysis.

6.1.2 Justification and limitations

It is necessary to review the significance of applying Inclusive Design approach to improve people's access to healthcare services. Similar to products, healthcare services also place demands on patients' capabilities along their care journeys. When the healthcare service's demands exceed the capabilities of a particular patient, exclusion or difficulty may arise. If healthcare service providers could consider these challenges when designing healthcare services, patients would be more likely to access care. Inclusive Design emphasises the contribution of understanding patients' diverse capabilities in informing service design decisions and thus including as many patients as possible.

The inclusive approach to healthcare service design is a user-focused system design process, rather than a single tool or method. The main focus in this thesis is to investigate the possibilities of applying Inclusive Design in healthcare service design. To answer the sub-research question 5, i.e., *What are the advantages and limitations of Inclusive Design as a means of improving people's access to healthcare services in the community*?, generally, an inclusive approach to designing healthcare services has the following advantages:

i) It helps understand patients' capability-related tasks by mapping patients' care journey;

ii) It can estimate current healthcare services' demands on patients' capabilities and the service exclusion on a population level;
iii) It can identify patients' capability-related challenges based on the demand and exclusion data, and further filter the data of patients' experiences and stories;

iv) It helps propose recommendations to meet patients' capability-related needs and thus improve patients' experiences of accessing the healthcare services.

This inclusive approach not only aids care providers, HCPs and healthcare researchers to consider patients' capabilities when designing healthcare services, but also can raise patients' awareness to know their own capability-related needs and actively request help. The output of step 4 *propose recommendation* in case study 2, i.e., "*Your COPD Care Reminder*", has set an example for how to engage patients in addressing their capability-related needs.

There are also a few limitations to this inclusive approach. Firstly, the population database used for estimating service demand and exclusion was limited to the data from Disability Follow-up to the Family Resources Survey in 1997. If we would like to have the most reliable exclusion data, more up-to-date patients' capability data are needed. Secondly, understanding how the current service delivery is the basis for utilising this inclusive approach, and this requires resources and time to collect patients' experiences and stories regarding how they receive healthcare services. If data is not sufficient, the estimation of the service's demands on patients' capabilities may not be reasonable, and the most difficult challenges for patients accessing healthcare services may not be identified and addressed. However, with a well-planned sampling and data analysis plan, for example, involving relating HCPs and providers as researchers, it is possible to cover the most representative samples within a limited time.

Also, if healthcare service providers do not understand how to specify the tasks of the patients' care journeys, or define the scope for estimating demands, they may not select the most appropriate way of using this approach. Some templates and associated instructions could be

designed to make it easier for service providers and HCPs who may not have a design background to use this approach. However, this research project is more focused on investigating the process of how to apply Inclusive Design principles to healthcare service design and not on creating new tools for an inclusive approach.

6.1.3 Comparison with existing models for healthcare service

There are a number of models i.e., the *model for improvement*, *systems approach*, the *ebd approach*, and *human factors* (introduced in Table 2.5*)* that have inspired the development of this inclusive healthcare design approach.

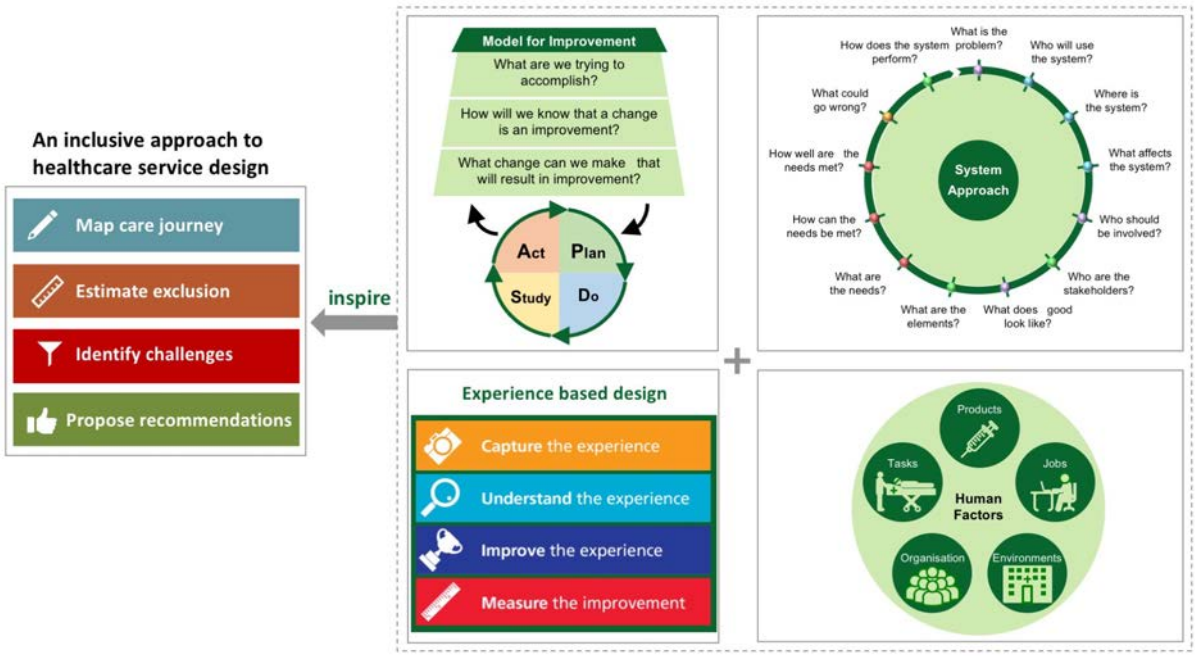


Figure 6.2 Models that inspire the development of an inclusive approach to healthcare service design

Specifically, the *model for improvement* aims to accelerate improvement based on three fundamental questions along with the Plan-Do-Study-Act cycle (see the left of Figure 6.3); and the *system approach* aims to deliver system-wide improvement by raising questions to encourage the integration of people, systems, design, risk and programme management (see the right of Figure 6.3). Both models contain a series of questions, which make the model more interactive and easier for healthcare providers to use. This has inspired the format of this inclusive approach. In addition, some of the questions within this *system approach* model have provided reference for designing the process of this inclusive approach. For example, questions such as "*who are the stakeholders?"* and *"who should be involved?"* could help to plan the sampling process of the inclusive approach.

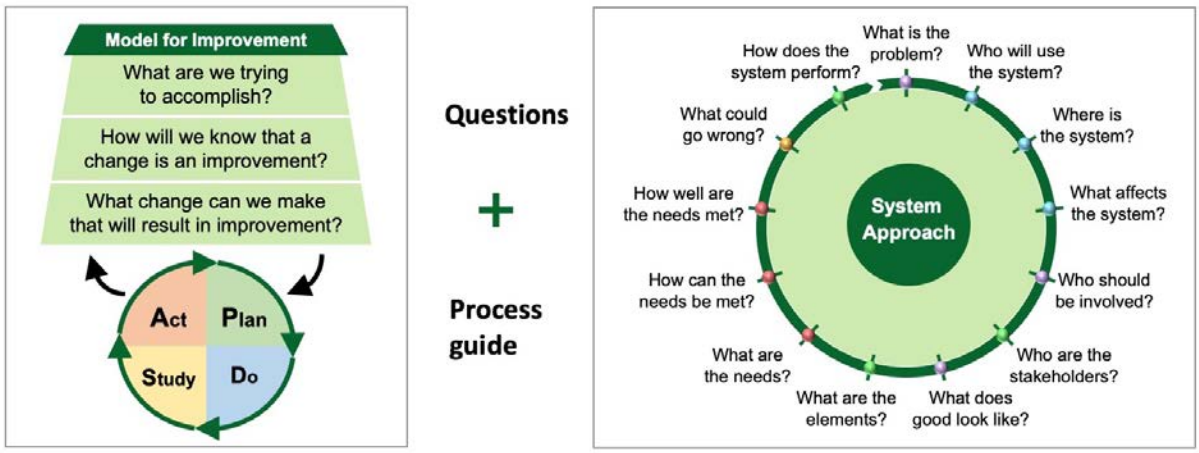


Figure 6.3 The *Model for Improvement* (left) and *System Approach* (right)

Both the *ebd approach* (see the left of Figure 6.4) and *human factors* have provided a reference in understanding patients' experiences (see the right of Figure 6.4).

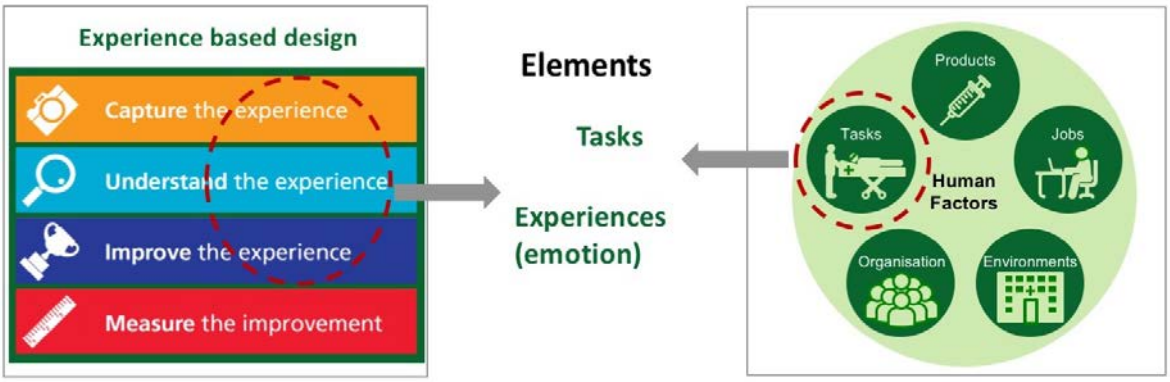


Figure 6.4 The *ebd* approach (left) and *Human Factors* (right)

The *ebd approach* emphases designing better experiences for patients, carers and staff, which has offered ideas concerning how to gather insight into patients' experiences. The *ebd* approach suggests that emotions are the route to understand people's experiences of the care process (NHS, 2009). *Emotion* is also considered in the process of the inclusive approach to healthcare service design. "*Human factors"* is a scientific discipline concerned with the understanding of interactions among humans and other systems, especially the interaction between the human and the thing of interests. It accounts for the design and evaluation of tasks, jobs, products, environments and systems in order to make them compatible with the needs, abilities and limitations of people. This is consistent with the idea of Inclusive Design in this context, i.e., the services' demands on people are not beyond their capabilities. Although "*human factors"* is often applied to technology and products, the tasks-analysis of the model informs the division of patients' care journeys in the inclusive approach.

6.1.4 Dissemination method

This approach has been disseminated to the HCPs who were interviewed and will be shared with healthcare researchers and service providers in back pain care and COPD care. Additional advertising could take place by presenting in healthcare-related conferences, such as *Design4Health* and *BMJ healthcare conference* and sharing with healthcare organisations and related care charities. Future work can also help stakeholders, such as commissioners of CCG and service providers, to learn how to use this approach to improve patients' access to healthcare services.

6.2 Ideas for further development and generality

Broadly, further work should seek to apply this inclusive approach to wider healthcare service design. There are three related questions which could be considered when further investigating the generality of this approach:
i) Can an inclusive approach be applied to other healthcare services including other long-term conditions and secondary healthcare service design?
ii) What is the scope of application for an inclusive approach?
iii) What are the advantages and disadvantages of applying an inclusive approach to healthcare service design?

Specifically, there remains a need to develop some assistance tools, which could guide healthcare providers and researchers who may have no design background in understanding and using this inclusive approach. For example, it would be useful to create templates for how to describe the challenges of patients and transfer the challenges into patients' potential needs in the third step *identify challenges* of this inclusive approach for novices. Other existing tools and methods could also be utilised to help carry out this approach. For instance, tools that might be useful in collecting patients' experiences in step 1 (*map care journey*) and tools could assist the evaluation of recommendations in step 4 (*propose recommendations*). To better promote the use of this inclusive approach in healthcare service design, it is also necessary to draw the attention of people such as healthcare service providers and researchers to the significance of Inclusive Design in healthcare service design. An introductions to Inclusive Design could be included at the beginning of this inclusive approach.

Meanwhile, it is essential to test and evaluate this approach in the healthcare industry. One solution is to seek cooperation from care providers to compare feedback on patients' experiences before and after applying this inclusive approach to designing the healthcare

services. Healthcare services such as PR could also compare the patients' uptake and attendance of PR before and after utilising an inclusive approach to evaluate the effectiveness of this approach.

6.3 Summary

This chapter presents an inclusive approach to improving healthcare service design based on the exploration of two case studies. The purpose of this inclusive approach to healthcare service design is to offer a supplement to existing healthcare improvement approaches rather than replacing the existing approaches or simplifying the improvement of complex systems.

Future work should seek to carry out further investigation into the development of this inclusive approach to healthcare service design, and the dissemination methods for advertising this approach. This research also highlights the importance of applying Inclusive Design principles to healthcare service design since the services' demands not beyond patients' capabilities are the prerequisite for patients accessing the healthcare services.

7 Conclusions and Further Work

This chapter summarises 1) the motivations and research questions, 2) contributions of this work, 3) reflections on the research methodology, and 4) suggestions for future work.

7.1 The motivations and research questions

The motivations mentioned at the beginning of the research project emphasised higher demand for healthcare services globally especially the services for long-term conditions in an ageing population. In the UK, the challenges of limited healthcare service resources and the Equality Act for services emphasise the importance of considering people's access to community rehabilitation services, which creates a potential opportunity for Inclusive Design, i.e., how to improve the accessibility of healthcare services for people who have different capabilities.

The motivations also highlighted the potential benefits of understanding users' capability-demand in a healthcare context: patients' capabilities to access healthcare services is the prerequisite for them to make use of these services. Although Inclusive Design has been widely applied in consumer products to understand users' diversity and inform design decisions to achieve business success, there is very little research explicitly investigating the application of Inclusive Design to healthcare delivery services. Therefore, there is an opportunity to produce evidence of how Inclusive Design can be applied to healthcare service design and explore the broader application of Inclusive Design.

The motivations also highlighted the need to raise healthcare providers' awareness and understanding of community-based rehabilitation services' demand on patients' capability and make recommendations to improve the accessibility of these services. There is little research that offers solutions to help healthcare researchers and care providers understand people's capability-related needs when accessing the healthcare services (as discussed in Chapter 6).

These motivations led to the overarching research question:

How can Inclusive Design be used to improve access to healthcare services in the community?

The overarching question was answered through a series of individual research questions addressed by the literature review and two case studies. The literature review contextualised

the research, i.e., "what are the challenges?", and answered the three sub-research questions below:

Sub-RQ1: *What is the state-of-the-art understanding and application of Inclusive Design?*

This sub-research question was addressed by reviewing the Inclusive Design's definition and philosophy, key theoretical concepts, methods and toolkits and industry application in Section 2.2. The literature review shows that Inclusive Design has been widely used in the accessibility of buildings and public transport, and consumer products (BS 8300, 2001; Department for Communities and Local Government, 2001; Clarkson *et al*., 2003). Although it has gradually been used in service sectors, there is still little evidence of research that applies Inclusive design to healthcare services design, in particular to specific healthcare services (Beniuk, Ward and Clarkson, 2011).

Sub-RQ2: *What are the challenges of an ageing population associated with community-based healthcare service delivery?*

This sub-research question was addressed by exploring three related topics in the literature: the need for community-based care, the accessibility of healthcare services and the care pathway (Section 2.3). Older people with long-term conditions tend to be the largest number of users of healthcare services, but the current services are fragmented and cannot meet patients' needs. Community-based care, which aims to provide care at or closer to home and avoid hospital admission, is the key to the future of the NHS but its accessibility requires improvement.

Sub-RQ3: *To what extent do people's capabilities affect their access to community-based healthcare services?*

This sub-research question was addressed by reviewing the literature on people's capabilities, healthcare experience, and self-management of long-term conditions in the community in Section 2.4. People's reduced capabilities could impact on their possibility to access healthcare services. By estimating community-based healthcare services' demands on patients' capabilities, the most challenging tasks and capability-related needs of patients can be identified along their care journeys, thus improving the services' access.

In addition to evidence from the literature, answering Sub-RQ3 also required data about patients' capability and the delivery of healthcare services to provide first-hand evidence that people's capabilities affect their access to community-based healthcare services. These data were analysed together with the following sub-research questions 4 and 5, which aimed to explore the application of Inclusive Design in improving people's access to healthcare services.

Sub-RQ4: *How can we use the principle of Inclusive Design to improve people's access to healthcare services along their care journey?*

This sub-research question was addressed through two case studies concerning the community-based rehabilitation services of back pain and COPD. The main findings from two case studies are summarised below:

1. Inclusive Design could be a guide used to specify patients' capability-related tasks along with their care journey and identify gaps in the current healthcare services. Applying the Inclusive Design approach to improving a healthcare service requires a clear picture of how the service is delivered and how patients access the current service system. The pre-defined (demand measure) scales of the Exclusion Calculator (an Inclusive Design tool, see Appendix B4) provide a reference for how precisely patients' tasks can be specified along their care journey and for estimating the service's demands and exclusion. Unlike ways in which a product is used, patients' ways of accessing a care service are more diverse and unpredictable. Hence, it is vital to clarify the selection standard and focus on typical tasks that patients are likely to go through, for example, the task, i.e., "*make a call*" is essential for people with back pain to access the telephone-based "Physio-Direct" service.

Moreover, some invisible gaps in the healthcare services can be identified during the process of mapping the patients' care journey. For example, in the back pain case study, care providers were likely to miss the service gap between "*after the telephone assessment*" and "*before patients receive written advice*" caused by patients potentially forgetting the verbal advice (see Figure 4.7 for details). Similarly, in case study 2, the service gap between "*after patients are informed of diagnosis*" and "*before they see the nurses*" has not been covered. Patients may feel depressed and anxious due to not receiving information about COPD and no support (see Table 5.7 for details).

2. The Inclusive Design tool (Exclusion Calculator) together with its "aided tools" could be used to estimate services' demands on patients and the service's exclusion. Hierarchal task analysis and the *Exclusion Calculator* (an Inclusive Design tool) can be used to estimate a service's demand on patients and the service's exclusion. Two "aided tools" of Inclusive Design, i.e., *personas* and *scenarios* could be used to define the scope for estimation (see pp. 96-98 for details). The demand of each task and the whole care journey could be assessed by the pre-defined scales which were constructed according to the 1996/97 Disability Follow-up to the Family Recourses Survey (Grundy *et al*., 1999, see Section 2.4.2.3 for more

information). The tasks that place a higher demand on patients' capabilities could be identified during the assessment. Meanwhile, the service's exclusion could be estimated based on the available capability data relating to the British population. In summary, Inclusive Design methods can help identify the service's demand on patients and estimate the service's level of exclusion.

3. Inclusive Design could identify the potential challenges and needs of patients when they access the service. There are two ways in which Inclusive Design could identify potential challenges: i) by consulting the estimated healthcare services' demand on patients and the service's exclusion number; ii) by further analysing the experience data of patients and HCPs from which the challenges and needs of patients could be extracted. The identified patients' challenges can be transferred into patients' potential needs. For example, patients with COPD may have difficulty in getting to the PR assessment venue which is relatively far and unfamiliar to them. This challenge can be interpreted as patients needing transport to support them to access the PR service.

4. Inclusive Design could help address patients' capability-related needs along their care journey and make the healthcare services more inclusive for patients to access. It is not uncommon for care providers to have different capability levels compared with patients, so they often tend to assume patients can do some "simple" tasks such as make a call and remember medical advice when designing a healthcare service. However, these "simple" tasks are beyond some patients' capabilities. An example was found in case study 1, where the task, "*read the leaflet and do exercise*", caused the largest percentage of the population to be excluded from the "Physio-Direct" service care journey (see Table 4.3). Some of the pictures within the exercise leaflet are not well-designed and lack clear procedures for patients to follow (see Figure 4.8), so patients could become confused by the picture and not benefit from the exercise. However, if these capability-related needs could be understood when the service is designed, e.g., by making the exercise diagrams clearer, patients would be less likely to be excluded from the service. Similarly, in case study 2, a couple of capability-related questions within "*Your COPD Care Reminder*" are designed to remind patients to consider whether their capabilities can meet the demand of some tasks along their care journeys in different scenarios. Patients are recommended to request help if they are unable to do some tasks. In this sense, Inclusive Design could improve patients' experience of accessing healthcare services.

Sub-RQ5: *What are the advantages and limitations of Inclusive Design as a means of improving people's access to healthcare services in the community?*

This sub-research question was addressed by the research process and findings from the two case studies, which together were summarised into an inclusive approach to healthcare services design. This inclusive approach integrates tools and steps to facilitate both healthcare providers' understanding of patients' capability-related needs and improvements to the healthcare services. There are some limitations of this inclusive approach, for example, the limitation due to the capability data, which could be addressed by future work. More discussions about limitations were presented in Section 6.1.2.

7.2 Contribution of this work

The research project is novel, not only exploring evidence that Inclusive Design could apply to healthcare services design, but also providing healthcare researchers and providers with a supplemental way of looking at patients' capability-related needs when designing healthcare services. The novelty and impact of this research are summarised in the sections below:

7.2.1 Novelty of the work

Although Inclusive Design has been widely used in the accessibility of buildings and public transport (BS 8300, 2001; Department for Communities and Local Government, 2001), there is a lack of research in the application of Inclusive Design to improve access to healthcare services. One previous work has applied Inclusive Design to the assessment of patients' experience within secondary care; it was not linked to any conditions (Beniuk, Ward and Clarkson, 2011). The two case studies in this thesis provide evidence that the application of Inclusive Design to specific health services is possible and that the tools can make a useful contribution to understanding service provision and hence service improvement. More importantly, the process of conducting Inclusive Design in healthcare services has the potential to draw providers, HCPs and researchers' attention to the details that may be ignored or be unknown regarding patients' access to services, for example, whether patients have the capability to make a GP appointment.

In addition, a range of design approaches has been applied to improve healthcare services, such as the *ebd approach* and *double diamond* (NHS Institute for Innovation and Improvement, 2009; Design Council, 2005). Each approach has its own focus and advantages in changing and improving healthcare services. For example, the *ebd approach* pays attention to patients' emotion along their care journeys and uses emotion as an indicator to measure improvement in healthcare services. So far, no practical approach exists that focuses on improving healthcare

services from the perspective of understanding patients' capability-related needs. My study shows how to apply Inclusive Design and its associated tools to identify the demands that healthcare services make of their users' capability and to estimate services' exclusion. It can help understand the diversity of patients' capability-related needs and propose recommendations to meet these needs, since access is a prerequisite for patients to use healthcare services. The process of applying Inclusive Design in this research may be used to improve other healthcare services.

This research also focuses on knowledge-generation, as recommended by Blessing and Chakrabarti (2009), rather than simply creating a tool and then validating it. A summary of an inclusive approach to healthcare service design could help care providers understand healthcare services' demands on patient's capabilities and make recommendations to improve the accessibility of these healthcare services. Many tools and methods are developed every year, but what is lacking is how to utilise the existing tools to assist in creating new understanding and knowledge. This inclusive approach is more like a process of guidance, which is not common, rather than tool development and validation. It is hoped that this exploratory process will inspire similar future research projects.

7.2.1 Impact of this research

The UK Equality Act 2010 promoted the importance of preventing the inequality of access for those with reduced capabilities, and Inclusive Design is one way of realising this improvement. As mentioned in case study 2, the National COPD Audit also demonstrated that COPD treatment might not be accessible to people with disabilities. This research has contributed to knowledge in a theoretical and practical way through the exploration and development of an inclusive approach to healthcare services design. It impacts on various aspects of both the healthcare industry and society:

i) Designing community-based rehabilitation with lower demand on patients' capabilities: patients with long-term conditions are more likely to access community-based healthcare services and self-manage their conditions, which could reduce hospital admission and save the social resources in healthcare;

ii) Raising care providers awareness of patients' capability-related needs, as well as offering a practical process for improving the accessibility of the healthcare services. This also echoes the equal access requirement of the UK Equality Act.

7.3 Reflections on the research methodology

The methodology used for this research project was based around the DRM framework, with some flexible adjustments and the inclusion of research tools learned from the Double Diamond and Design Wheel (see Section 3.3 for details). Specifically, the DRM framework contains four stages, *research clarification* (RC), *descriptive study I* (DS-I), *prescriptive study* (PS), and *descriptive study* II (DS-II), which provided an excellent framework for positioning and answering the research question.

An inclusive approach to healthcare services design, which focuses on understanding patients' capability-related tasks, demands, challenges and needs when they access healthcare services was proposed. It is a user-focused system design process. Inclusive Design methods (tools) together with tools and methods from other domains such as ethnography and service design are utilised to facilitate this approach. The two case studies of this research could also provide references for other healthcare researchers and providers. Figure 7.1 summarises the main steps, support tools and methods, as well as outputs of this inclusive healthcare design approach. This approach will be disseminated to healthcare researchers and service providers. It will also be advertised through healthcare research organisations, healthcare-related conferences and forums, as well as social media where possible.

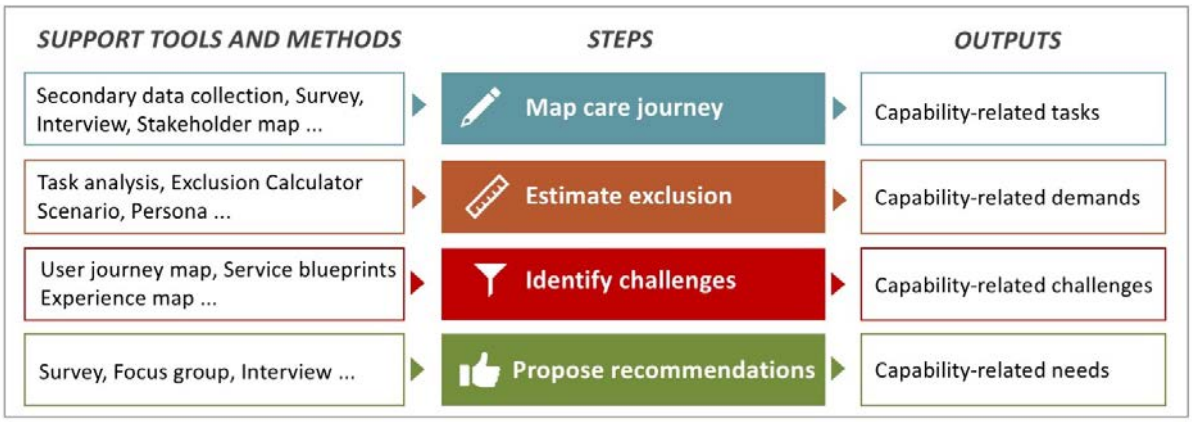


Figure 7.1 Main steps and tools to an inclusive healthcare design approach

However, there were some limitations due to inevitable challenges within the nature of the work. For example, the fourth stage of the DRM framework is the evaluation of the developed support. In this research, the *inclusive approach to healthcare services design* was just evaluated based on feedback from the patients and HCPs and has not been evaluated in the healthcare industry. It is is very difficult to evaluate an intervention (approach) in the health industry due to challenges such as access to patients as well as HCPs and the up to one year

period for ethics application. Although this is a limitation of the research, Blessing and Chakrabarti (2009) recommended in the DRM book not to unduly develop a tool and test it in practice since it could lead to a large number of tools and many of them may not be widely used if they do not fit into design practice. Therefore, instead of evaluating the approach, this research was more focused on proposing recommendations and integrating them into an approach. Future work would be to evaluate and refine the approach in practice.

This *inclusive approach to healthcare services design* was summarised based on two case studies which showed the benefit of applying Inclusive Design not only in understanding patients' capability-needs along their care journeys, but also in helping to identify specific concerns, such as gaps in healthcare services within the care journey. This provides part of the answers to the overarching research question, *How can Inclusive Design be used to improve access to healthcare services in the community?* However, whether it can be applied to wider healthcare service design still needs to be explored.

In addition, it might be difficult for healthcare providers and researchers who have no design background to understand and use this inclusive approach, so some helpful tools and instructions should be developed.

Overall, this research project successfully involved patients and HCPs in terms of participating in and supporting the research, thus providing first-hand evidence from the healthcare service industry rather than merely basing results on the existing healthcare database. It has achieved the target of this PhD research, i.e., type 3 of the DRM framework (see Figure 3.7).

7.4 Further work

Suggestions for future work can be divided into three categories: Inclusive Design (including theory and databases for Inclusive Design), the application scope of Inclusive Design in healthcare services, and the evaluation and refinement of the particular inclusive approach used in this thesis.

Inclusive Design (including theory and databases for Inclusive Design): Inclusive Design methods and tools consider physical and cognitive exclusion. Other types of exclusion, for instance social or psychological exclusion, were not included in this analysis to estimate the healthcare service's exclusion. In addition, some psychological factors, such as motivation, play a vital role in improving patients' experiences of accessing healthcare services. Future

research could explore the theory of Inclusive Design from psychological perspectives and develop relevant methods and tools to more precisely estimate cognitive exclusion.

Another critical factor that affects estimates of a service's exclusion is people's capability database. Currently, the exclusion data is based on the general population rather than specific medical conditions. Although the database can filter data for a particular disease, it is not a realistic way of estimating service exclusion in the long term. Therefore, establishing a database of patients' capabilities based on their condition could be considered fundamental work in the future.

The application scope of Inclusive Design in the healthcare services: The research procedure was used in two case studies and specified in community-based rehabilitation. Whether it could be adapted and applied to other healthcare services and conditions still needs to be further explored. Also, it is useful to investigate the most suitable application scope for applying Inclusive Design to the improvement of healthcare services.

The evaluation and refinement of this inclusive approach: The evaluation of this inclusive approach in the health industry is difficult due to challenges such as ethical approval and resources. A full evaluation of an invention (approach) is beyond the timeline of a PhD study, but could be potential work for post-doctoral research.

As mentioned in Section 6.1.2, it is necessary to refine this inclusive approach and make it easier for healthcare providers and researchers who may not know Inclusive Design to understand and use this approach. Some possible solutions, e.g., developing some tools to provide people with guidance about how to use this inclusive approach, can be developed in future work.

References

Ainsworth, L. and Marshall, E. (1998). Issues of quality and practicability in task analysis: Preliminary results from two surveys. *Ergonomics*, 41(11), pp. 1607-1617.

Albrand, G., Munoz, F., Sornay-Rendu, E., DuBoeuf, F. and Delmas, P. D. (2003). Independent predictors of all osteoporosis-related fractures in healthy postmenopausal women: the OFELY study. *Bone*, *32*(1), pp. 78-85.

Alexander, K., Clarkson, P.J., Bishop, D. and Fox, S. (2001). *Good design practice for medical devices and equipment – a framework*. University of Cambridge, Engineering Design Centre. ISBN 1-902546–08-3.

Anastas, J. W. (1999). *Research design for social work and the human services*. 2nd ed. New York, NY: Columbia University Press.

Andersen, R. (1968). *A behavioral model of families' use of health services*. Research series no. A25, Center for Health Administration Studies, Chicago, Ill.: University of Chicago Press.

Annett, J. and Duncan, K. (1967). Task Analysis and Training Design. *Occupational Psychology*, 41, pp. 211-221.

Annett, J. (2003). Hierarchical task analysis. In: *Handbook of cognitive task design*. CRC Press, pp. 41-60.

Baker, S. E. and Edwards, R. (2012). *How Many Qualitative Interviews Is Enough? National Centre for Research Methods Review Paper*. http://eprints.ncrm.ac.uk/2273/ [Accessed 20 May 2016].

Barr, R. G., Celli, B. R., Martinez, F. J., Ries, A. L., Rennard, S. I., Reilly Jr, J. J., Sciurba, F. C., Thomashow, B. M. and Wise, R. A. (2005). Physician and patient perceptions in COPD: the COPD resource network needs assessment survey. *The American journal of medicine*, *118*(12), pp. 1415-e9.

Bazeley, P. and Jackson, K. (Eds.) (2013). *Qualitative data analysis with NVivo*. Sage Publications Limited.

BBC News (2008). Q&A: Social care. *BBC News*. [online] Available at: http://news.bbc.co.uk/1/hi/health/4858610.stm

BBC News (2013). The changing NHS. *BBC News*. [online] Available at: http://www.bbc.co.uk/news/health-19674838

BBC News (2018). NHS England to stop 'ineffective' treatments. *BBC News*. [online] Available at: https://www.bbc.co.uk/news/health-44665560

Beniuk, C., Ward, J. and Clarkson, P. J. (2011). Applying inclusive design principles in the assessment of healthcare services. In: *Proceedings of on Design 4 Health*. Sheffield, UK, 13-15th July 2011, pp. 22-36.

Benktzon, M. (1993). Designing for our future selves: the Swedish experience. *Applied Ergonomics*, 24(1), pp. 19-27.

Blaikie, N. (2000). *Designing Social Research*. Cambridge: Polity.

Blessing, L. T. and Chakrabarti, A. (2009). *DRM, A Design Research Methodology*. Springer-Verlag London.

Blessing, L. T., Chakrabarti, A. and Wallace, K. M. (1992). Some issues in engineering design research. In: *Proceedings of EDC/SERC Design Methods Workshop*. The Open University UK.

Blessing, L. T., Chakrabarti, A. and Wallace, K. M. M. (1995). A design research methodology. In: *Proceedings of the 10th International Conference on Engineering Design (ICED'95)*. 23, pp. 50-55.

Bolton, C. E., Bevan-Smith, E. F., Blakey, J. D., *et al*. (2013). The BTS Guideline on Pulmonary Rehabilitation in Adults. *Thorax*, 68, pp. 1-30. [online] Available at: https://www.brit-thoracic.org.uk/guidelines-and-qualitystandards/pulmonary-rehabilitationguideline/ [Accessed 15 March 2016].

Bowen, G. A. (2009). Document Analysis as a Qualitative Research Method. *Qualitative Research Journal*, 9(2), pp. 27-40. [online] Available at: https://doi.org/10.3316/QRJ0902027

Bowling, A., Rowe, G. and McKee, M. (2013). Patients' experiences of their healthcare in relation to their expectations and satisfaction: a population survey. *Journal of the Royal Society of Medicine*, 106(4), pp. 143-149.

British Lung Foundation (2012). *Chronic Obstructive Pulmonary Disease (COPD) statistics*. [online] Available at: http://statistics.blf.org.uk/copd [Accessed 20 May 2016].

British Standards Institute (2005). *BS 7000-6:2005: Design management systems - Managing Inclusive Design - Guide*.

Bryant, C. (2017). *What is 'Lean Thinking' and can it really help to improve Patient Care*?

Bryman, A. (2004). *Social research methods*. 2nd ed. New York: Oxford University Press, p. 592.

BS 8300 (2001). Design of buildings and their approaches to meet the needs of disabled people - Code of practice.

Cambridgeshire Community Services NHS Trust (2016). *Back Exercises*. [online] Available at: http://www.eoemskservice.nhs.uk/advice-and-leaflets/lower-back

Canada Health Infoway. *Change Management Toolkit: Leading Change in Health Care*. [online] Available at: https://www.infoway-inforoute.ca/en/resource-centre/toolkits/change-management [Accessed 16 Sept 2018].

Card, S. K., Moran, T. P. and Newell, A. (1983). *The Psychology of Human-Computer Interaction.* Hillsdale, New Jersey: Lawrence Erlbaum Associates Inc.

Cardoso, C., Keates, S. and Clarkson, P. J., (2005). Are users necessary for inclusive design? In: *Proceedings ICED 05, the 15th International Conference on Engineering Design*, Melbourne, Australia.

Cawthon, P. M., Fullman, R. L., Marshall, L., Mackey, D. C., Fink, H. A., Cauley, J. A., Cummings, S. R., Orwoll, E. S. and Ensrud, K. E. (2008). Physical performance and risk of hip fractures in older men. *Journal of Bone and Mineral Research*, *23*(7), pp. 1037-1044.

Center for Devices and Radiological Health (1997). *Design Control Guidance For Medical Device Manufacturers*.

Challis, D., Hughes, J., Berzins, K., Reilly, S., Abell, J. and Stewart, K. (2010). *Self-care and Case Management in Long-term Conditions: The effective management of critical interfaces*. London: HMSO. Available at: http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1715-201_V01.pdf [Accessed 19 April 2018].

Chamberlain, M., Esquivel, J., Miller, F. and Patmore, J. (2015). BT's Adoption of Customer Centric Design. *Applied Ergonomics*, 46(B), pp. 279-283.

Chamberlain, P., Mawson, S.J. and Wolstenholm, D. (2017) Service Design in Chronic Health. In: Tsekleves, E. and Cooper, R., (eds.) *Design for Health. Design for Social Responsibility* . Routledge , pp. 216-240. ISBN 9781472457424

Clarkson, J. and Eckert, C. (2010). *Design process improvement: a review of current practice*. Springer Science & Business Media.

Clarkson, P. J., Coleman, R., Keates, S., and Lebbon, C. (Eds.) (2003). *Inclusive Design: Design for the Whole Population*. London, UK: Springer.

Clarkson, P. J. and Coleman, R. (2015). History of Inclusive Design in the UK. *Applied Ergonomics*, 46, pp. 233-324.

Clarkson, P. J., Coleman, R., Hosking, I. and Waller, S. (2007). *Inclusive Design Toolkit*. Engineering Design Centre. [online] Available at: http://www.inclusivedesigntoolkit.com. [Accessed 13 November 2017]

Clarkson, P. J. and Keates, S. (2003). User capabilities and product demands. In: *Proceedings of the International Conference on Inclusive Design and Communications*. pp. 384-389.

Charles, A., Ham, C., Baird, B., Alderwick, H. and Bennett, L. (2018). *Reimagining community services - Making the most of our assets*. The King's Fund.

Cohen, L., Manion, L. and Morrison, K. (2007). *Research methods in education*. 6th ed. New York: Routledge/Taylor & Francis Group.

Coleman, R. (1994). The case for inclusive design – an overview. In: *Proceedings of the 12-triennial congress, International Ergonomics Association and Human Factors of Canada, Toronto*, 3, pp. 250-252.

Coleman, R., Clarkson, P. J., Dong, H. and Cassim, J. (2007). *Design for Inclusivity: A Practical Guide to Accessible, Innovative and User-Centred Design*. Aldershot (UK): Gower Publishing Ltd.

Cooper, R., Kuh, D., Cooper, C., Gale, C. R., Lawlor, D. A., Matthews, F., Hardy, R. and FALCon and HALCyon Study Teams (2011). Objective measures of physical capability and subsequent health: a systematic review. *Age and ageing*, *40*(1), pp. 14-23.

Corben, S. and Rosen, R. (2005). *Self-management for Long-term Conditions: Patients' perspectives on the way ahead*. The King's Fund.

Cooper, A. (1999). *The Inmates Are Running the Asylum*. Leipzig: Sams Indianapolis. [online] Available at: https://doi.org/10.1007/978-3-322-99786-9_1

Coulter, A., Roberts, S. and Dixon, A. (2013). *Delivering better services for people with long-term conditions - Building the house of care.* London: The King's Fund.

Cox, N. S., Oliveira, C. C., Lahham, A. and Holland, A. E. (2017). Pulmonary rehabilitation referral and participation are commonly influenced by environment, knowledge, and beliefs about consequences: a systematic review using the Theoretical Domains Framework. *Journal of Physiotherapy*, *63*(2), pp. 84-93.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. Sage.

Curry, N. (2015). *Fact or fiction? Demand for GP appointments is driving the 'crisis' in general practice*. Nuffield Trust comment.

de Iongh, A. (2014). Patients need support to self-manage their long-term Conditions. *BMJ*, 348, p. g2973. [online] Available at: doi: https://doi.org/10.1136/bmj.g2973

Demirbilek, O. (1999). *Involving the Elderly in the Design Process: A Participatory Design Model for Usability, Safety and Attractiveness*. PhD. Bilkent University. http://hdl.handle.net/11693/18560

Department for Communities and Local Government (2001). *Planning Policy Guidance 13: Transport.* ISBN: 0 11 753558. [online] Available at: https://webarchive.nationalarchives.gov.uk/20120919160424/http://www.communities.gov.uk/archived/publications/planningandbuilding/ppg13

Department of Health (2012a). *Long Term Conditions Compendium of Information*. 3rd ed. Available at: https://www.gov.uk/government/publications/long-term-conditions-compendium-of-information-third-edition

Department of Health (2012b). National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care.

Department of Social Security Social Research Branch (2000). Disability Follow-up to the 1996/97 Family Resources Survey [computer file]. Colchester, Essex: UK Data Archive [distributor], 3 March 2000. SN: 4090.

Design Council (2005). *11 lessons: Managing design in 11 global brands*. [online] Available at:

https://www.designcouncil.org.uk/sites/default/files/asset/document/ElevenLessons_Design_Council%20%282%29.pdf

Design Council (2008). *Inclusive Design Education Resource*. London: Design Council. [online] Available at: http://www.designcouncil.info/inclusivedesignresource/index.html

Designing Our Tomorrow (2018). *Designing Our Tomorrow*. [online] Available at: https://www.education.designingourtomorrow.com

Eckert, C., Clarkson, P. J. and Stacey, M. (2003). The spiral of applied research: a methodological view on integrated design research. Design Society. In: *Proceedings of the 14th International Conference on Engineering Design (ICED'03)*, Stockholm, Sweden.

Economic Social Research Council (no date). *What is ethics*? [online] Available at: https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/frequently-raised-questions/what-is-ethics/

Edwards, N. (2014). *Community services How they can transform care*. The King's Fund.

Engineering Design Centre (2007). *Exclusion Calculator*. [online] Available at: http://calc.inclusivedesigntoolkit.com/

Ettinger, W. H., Fried, L. P., Harris, T., Shemanski, L., Schulz, R., Robbins, J. and C.C.R. Group. (1994). Self-Reported Causes of Physical Disability in Older People: The Cardiovascular Health Study. *Journal of the American Geriatrics Society*, 42(10), pp. 1035-1044.

European Patients Forum (2016). *Defining and Measuring Access to Healthcare: the Patients' Perspective - Position Statement*.

Foster, N.E., Williams, B., Grove, S., Gamlin, J. and Salisbury, C. (2011). The evidence for and against 'PhysioDirect' telephone assessment and advice services. *Physiotherapy*, 97, pp. 78-82.

Freburger, J. K., Holmes, G. M., Agans, R. P., Jackman, A. M., Darter, J. D., Wallace, A. S., Castel, L. D., Kalsbeek, W. D. and Carey, T. S. (2009). The Rising Prevalence of Chronic Low Back Pain. *Arch Intern Med*., 169(3), pp. 251-258.

Frenk, J. (1992). The concept and measurement of accessibility. In: *Health Services Research: An Anthology*. Edited by White, K.L., Frenk, J., Ordonez, C., Paganini, J. M. and Starfield, B. Washington: Pan American Health Organization, pp. 858-864.

Fry, K. (2017). Why Hospitals Need Service Design: Challenges and methods for successful implementation of change in hospitals. [online] Available at: https://www.ntnu.edu/documents/139799/1273574286/TPD4505.Kristine.Rise.Fry.pdf/1568d6be-df14-4c51-9820-e690d354bf2b

Gershlick, B. and Firth, Z. (2017). *Provision of community care: who, what, how much?* The Health Foundation.

Goddard, M. and Smith, P. (2001). Equity of access to health care services: theory and evidence from the UK. *Social Science & Medicine*, 53(9), pp. 1149-1162.

Goldsmith, S. (1997). *Designing for the Disabled: The New Paradigm*. Routledge.

Goodman-Deane, J., Ward, J., Hosking, I. and Clarkson, P. J. (2014). A comparison of methods currently used in inclusive design. *Applied Ergonomics*, 45(4), pp. 886-894. [online] Available at: https://doi.org/10.1016/j.apergo.2013.11.005

Gordon, K. and Rice, H., 2015. *Barriers to Self-Management of Chronic Pain in Primary Care*.

Government Office for Science (2016). Future of an Ageing Population. *Crown*. [online] Available at: https://www.ageing.ox.ac.uk/files/Future_of_Ageing_Report.pdf

Greenway, T. (2017). How community-based care is putting patients in control. *Health Awareness*. http://www.healthawareness.co.uk/transforming-healthcare/how-community-based-care-is-putting-patients-in-control

Griffiths, T. L., Burr, M. L., Campbell, I. A., Lewis-Jenkins, V., Mullins, J., Shiels, K., Turner-Lawlor, P. J., Payne, N., Newcombe, R. G., Lonescu, A. A. and Thomas, J. (2000) Results at 1 year of outpatient multidisciplinary pulmonary rehabilitation: a randomised controlled trial. *The Lancet*, 355(9201), pp. 362-368.

Grix, J. (2002). Introducing students to the generic terminology of social research. *Politics*, 22(3), pp. 175-186.

Grundy, M., Ahlburg, D., Ali, M. and Sloggett, A. (1999). *Disability in Great Britain: Results from the 1996/7 Disability Follow-Up to the Family Resources Survey, DSS Research Report No. 94*. London: HMSO.

Guba, E. ed., (1990). *The paradigm dialog*. London: Sage Publications.

Harris, D., Hayter, M. and Allender, S. (2008). Factors affecting the offer of pulmonary rehabilitation to patients with chronic obstructive pulmonary disease by primary care professionals: a qualitative study. *Primary Health Care Research & Development*, *9*(4), pp. 280-290.

Hay, C. (2002). *Political Analysis. A Critical Introduction*. Basingstoke: Palgrave.

Health and Social Care Information Centre (2014) Community care statistics, social services activity, England – 2013-14, final release. [Online] Available from: http://www.hscic.gov.uk/catalogue/PUB16133/comm-care-stat-act-eng-2013-14-fin-anxe.xls.

Helen Hamlyn Centre for Design (2010). *Design with People*. Royal College of Art. [online] Available at: http://designingwithpeople.rca.ac.uk

Herssens, J. (2013). Design(ing) for more – towards a global design approach and local methods. In: *Include Asia 2013*. Hong Kong: Helen Hamlyn Research center.

Hignett, S. (2012). Can inclusive environmental design be achieved in acute hospitals? In: *Proceedings of the 2nd International Conference on Human Factors and Ergonomics in Healthcare*. San Francisco, USA, pp.577-584.

HM Government (2012). *Caring for our future: reforming care and support*. ISBN: 9780101837828

Hoy, D., March, L., Brooks, P., Blyth, F., Woolf, A., Bain, C., Williams, G., Smith, E., Vos, T., Barendregt, J., Murray, C., Burstein, R. and Buchbinder, R. (2014). The global burden of low back pain: estimates from the Global Burden of Disease 2010 study. *Annals of the Rheumatic Diseases*, 73(6), pp. 968-974.

Hollnagel, E., Wears, R.L. and Braithwaite, J. (2015). *From Safety-I to Safety-II: A White Paper*.

Hussein, S. and Partridge, M. (2002). Perceptions of asthma in South Asians and their views on educational materials and self-management plans: a qualitative study. *Patient education and counseling*, *48*(2), pp. 189-194.

INOCOSE UK (2009). *What is Systems Engineering*? [online] Available at: http://incoseonline.org.uk/Program_Files/Publications/zGuides_1.aspx?CatID=Publications [Accessed on 16 Sept 2018].

International Ergonomics Association (2018). *Definition and Domains of Ergonomics*. [online] Available at: https://www.iea.cc/whats/index.html [Accessed on 16 Sept 2018].

Israel, M. (2014). *Research ethics and integrity for social scientists: Beyond regulatory compliance*. 2nd ed. London: Sage. p. 208.

Johnson, D., Clarkson, P.J. and Huppert, F. (2010). Capability measurement for inclusive design. *Journal of Engineering Design*, 21(2/3), pp. 275-88.

Johnston, K., Grimmer-Somers, K., Young, M., Antic, R. and Frith, P. (2012a). Which chronic obstructive pulmonary disease care recommendations have low implementation and why? A pilot study. *BMC Research Notes*, *5*(1), p. 652.

Johnston, C. L., Maxwell, L. J., Maguire, G. P. and Alison, J. A. (2012b). How prepared are rural and remote health care practitioners to provide evidence-based management for people with chronic lung disease? *Australian journal of rural health*, *20*(4), pp. 200-207.

Jones, P. (2013). *Design for Care: Innovating Healthcare Experience*. New York: Rosenfeld Media.

Kalbach, J. (2016). *Mapping experiences: A complete guide to creating value through journeys, blueprints, and diagrams*. O'Reilly Media, Inc.

Keates, S. and Clarkson, P. J. (2003). *Countering Design Exclusion: An introduction to inclusive design*. London, UK: Springer-Verlag.

Keating, A., Lee, A. and Holland, A. E. (2011). What prevents people with chronic obstructive pulmonary disease from attending pulmonary rehabilitation? A systematic review. *Chronic Respiratory Disease*, *8*(2), pp. 89-99.

Kuhn, T.S. (2012). The Structure of Scientific Revolutions. (4th ed.). *Chicago: University of Chicago Press*. ISBN 978-0-226-45812-0.

Langley, G. J., Moen, R. D., Nolan, K. M., Nolan, T. W., Norman, C. L. and Provost, L. P. (2009). *The improvement guide: a practical approach to enhancing organizational performance*. 2nd ed. John Wiley & Sons.

Lee, D. (2017). A model for designing healthcare service based on the patient experience. *International Journal of Healthcare Management*, 1-9.

Lee, S. (2011). Evaluating serviceability of healthcare servicescapes: Service design perspective. *International Journal of Design, 5*(2), 61-71.

Levesque, J.F., Harris, M.F. and Russell, G. (2013). Patient-centred access to health care: conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health*, 12(18), pp. 1-9. http://doi.org/10.1186/1475-9276-12-18

Liu, Y., Dickerson, Y., Waller, S. D., Waddingham, P. and Clarkson, P. J. (2018). The role of Inclusive Design in improving peoples' access to treatment for back pain. In: *Breaking Down Barriers: Usability, Accessibility, and Inclusive Design*. pp. 195-206.

Luchinskaya, D., Simpson, P. and Stoye, G. (2017). *Chapter 5: UK health and social care spending. IFS Green Budget: February 2017*. Institute of Fiscal Studies.

Lustick, B. (2002). Common back pain misunderstandings. *Back Be Nimble Newsletter*.

Maddocks, M., Kon, S. S., Canavan, J. L., Jones, S. E., Nolan, C. M., Labey, A., Polkey, M. I. and Man, W. D. (2016). Physical frailty and pulmonary rehabilitation in COPD: a prospective cohort study. *Thorax*, 71, pp. 988-995.

Manley, D. ed (1986) *New Design For Old*. Victoria and Albert Museum and Helen Hamlyn Foundation, London.

Mapstone, N. (2000). *Fully Equipped: The Provision of Equipment to Older or Disabled People by the NHS and Social Services in England and Wales*. London: Audit Commission Publications.

Martin, J., Meltzer, H. and Elliot, D. (1988). *The prevalence of disability among adults. Office of Population Censuses and Surveys*, Social Survey Division, HMSO, London, UK.

Mason, M. (2010). Sample Size and Saturation in PhD Studies Using Qualitative Interviews. *Forum: Qualitative Social Research*. [online] Available at: http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027 [Accessed 10 Dec 2016].

Mathar, H., Fastholm, P., Hansen, I. R. and Larsen, N. S. (2015). Why Do Patients with COPD Decline Rehabilitation? *Scandinavian Journal of Caring Sciences*, 30, pp. 432-441.

May, S. (2010). Self-management of chronic low back pain and osteoarthritis. *Nature Reviews Rheumatology*, 6, pp. 199-209.

McCarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E. and Lacasse, Y. (2015). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *The Cochrane Database of Systematic Reviews*, 4, pp. 1-54.

McClean, S., Brilleman, S. and Wye, L. (2015). What is the perceived impact of Alexander technique lessons on health status, costs and pain management in the real life setting of an English hospital? The results of a mixed methods evaluation of an Alexander technique service for those with chronic back pain. *BMC Health Services Research*, 15(1), p. 293.

Microsoft (2015). *Inclusive: A Microsoft Design Toolkit*. Microsoft 2015 Licensed under Creative Commons Attribution - NonCommercial-NoDerivatives (CC BY-NC-ND). https://www.microsoft.com/en-us/design/inclusive

Morgan, D. L. (2007). Paradigms lost, and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*, 1, pp. 48-76. DOI: 10.1177/ 2345678906292462 27 177

Mortimer, J. and Green, M. (2015). *Briefing: The Health and Care of Older People in England 2015*. London: Age UK.

Murray, C. J. L., Richards, M. A., Newton, J. N., Fenton, K. A., Anderson, H. R., Atkinson, C. *et al.* (2013). UK health performance: Findings of the global burden of disease study 2010. *Lancet*, 381, pp. 997-1020.

Myerson, J., West, J. (2015). Make It Better: how universal design principles can have an impact on healthcare services to improve the patient experience. *Universal Design in Education*, Dublin, Ireland, 12-13 November 2015.

National Institute for Health and Clinical Excellence (NICE) (2011). *COPD Costing Report*.

National Institute for Health and Clinical Excellence (2010). *Chronic obstructive pulmonary disease in over 16s: diagnosis and management. COPD Guideline CG101*. [online] Available at: http://guidance.nice.org.uk/CG101 (Accessed 20 May 2016).

National Institute for Health and Clinical Excellence (2016). *Low back pain and sciatica in over 16s: assessment and management - NICE guideline [NG59]*. [online] Available at: https://www.nice.org.uk/guidance/ng59

NHS England (2017a). *NHS England Funding and Resource 2017-19: supporting 'Next Steps for the NHS Five Year Forward View'*. [online] Available at: https://www.england.nhs.uk/wp-content/uploads/2017/03/nhse-funding-resource-supporting-fyfv.pdf

NHS England (2017b). *Involving people in their own health and care: Statutory guidance for clinical commissioning groups and NHS England*. [online] Available at: https://www.england.nhs.uk/publication/involving-people-in-their-own-health-and-care-statutory-guidance-for-clinical-commissioning-groups-and-nhs-england/

NHS England (2018). *The Change Model Guide*.

NHS Improvement (2018). *Driver diagrams (tree diagrams)*. [online] Available at: https://improvement.nhs.uk/documents/2109/driver-diagrams.pdf (Accessed on 16 Sept 2018).

NHS Institute for Innovation and Improvement (2009). *The ebd Approach*.

NHS Service Specification (2012). *Commissioning toolkit for respiratory services*. [online] Available at: https://www.gov.uk/government/publications/commissioning-toolkit-for-respiratory-services [Accessed 15 March 2015].

Nicolle, C., Hewer, S., Lebbon, C. and Kingsland, C. (2005). Coming of age - an inclusive design resource comes to fruition. In: *Proceedings of International Conference on Inclusive Des*ign (ICED 2005). London: The Design Society.

Nielsen, L. (2012). Personas. In: Soegaard, M. and Dam, R. F. (2012). *The Encyclopedia of Human-Computer Interaction*. 2nd ed. Aarhus, Denmark: The Interaction Design Foundation, [online] Available at: http://www.interaction-design.org/encyclopedia/personas.html

Norman, D. A., (2005). Human-centered design considered harmful. *Interactions*, *12*(4), pp. 14-19.

Office for National Statistics (2017a). *National Population Projections: 2016-based statistical bulletin*.

Office for National Statistics (2017b). *Overview of the UK population: July 2017*.

Office for National Statistics (2017c). *Sickness absence in the labour market: 2016. Analysis describing sickness absence rates of workers in the UK labour market*.

Oliver, A. and Mossialos, E. (2004). Equity of access to health care: outlining the foundations for action. *Journal of Epidemiology & Community Health*, 58, pp. 655-658.

Oxford English Dictionary. [online] Available at: https://www.oxforddictionaries.com

Panella M., Marchisi, S. and Di Stanisla, F. (2003). Reducing clinical variations with clinical pathways: Do pathways work? *International Journal for Quality in Health Care*, 15, pp. 509-521.

Patient access partnership. *5A's of Access*. [online] Available at: http://www.eupatientaccess.eu/page.php?i_id=19

Pellicore, S. (2016). *What's the difference between access and accessibility?* [online] Available at: https://www.quora.com/Whats-the-difference-between-access-and-accessibility

Penchansky, R. and Thomas, J. W. (1981). The concept of access: definition and relationship to consumer satisfaction. *Med Care*, 19(2), pp. 127-40. [online] Available at: http://www.ncbi.nlm.nih.gov/pubmed/7206846/

Perez, X., Wisnivesky, J. P., Lurslurchachai, L., Kleinman, L. C. and Kronish, I. M. (2012). Barriers to adherence to COPD guidelines among primary care providers. *Respiratory Medicine*, *106*(3), pp. 374-381.

Persad, U., Langdon, P. and Clarkson, P. J. (2007). Characterising user capabilities to support inclusive design evaluation. *Universal Access in the Information Society*, 6(2), pp. 119-135.

Pierobon, A., Bottelli, E. S., Ranzini, L., Bruschi, C., Maestri, R., Bertolotti, G., Sommaruga, M., Torlaschi, V., Callegari, S. and Giardini, A. (2017). COPD patients' self-reported adherence, psychosocial factors and mild cognitive impairment in pulmonary rehabilitation. *International Journal of Chronic Obstructive Pulmonary Disease*, *12*, pp. 2059-2067.

Punch, K. F. (2005). *Introduction to social research: Quantitative and qualitative approaches*. Sage.

Purdy, S. (2010). *Avoiding Hospital Admissions. What does the research evidence say?* London: The King's Fund. [online] Available at: www.kingsfund.org.uk/publications/avoiding_hospital.html [Accessed on 19 April 2018].

Robineau, D. (2016). Ageing Britain: two-fifths of NHS budget is spent on over-65s. *The Guardian*. [online] Available at: https://www.theguardian.com/society/2016/feb/01/ageing-britain-two-fifths-nhs-budget-spent-over-65s

Robson, C. and McCartan, K. (2016). *Real world research: a resource for users of social research methods in applied settings*. 4th ed. Chichester, West Sussex, United Kingdom: Wiley.

Royal Academy of Engineering (2017). *Engineering better care - a systems approach to health and care design and continuous improvement*.

Royal College of Physicians (2015). *Pulmonary Rehabilitation: Time to breathe better*. National COPD Audit Programme. [online] Available at: https://www.brit-thoracic.org.uk/standards-of-care/audit/national-copd-audit-programme/ [Accessed 20 May 2016].

Royal College of Physicians (2016). *National COPD Audit 2013-2016*. [online] Available at: https://www.brit-thoracic.org.uk/audit-andqualityimprovement/national-copd-audit-2013-–-2016/ [Accessed 17 March 2016].

Ritchie, J. and Lewis, J. (2003). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage Publications.

Salisbury, C., Montgomery, A. A., Hollinghurst, S., Hopper, C., Bishop, A., Franchini, A., Kaur, S., Coast, J., Hall, J., Grove, S. and Foster, N. E. (2013). Effectiveness of Physio Direct telephone assessment and advice services for patients with musculoskeletal problems: pragmatic randomised controlled trial. *BMJ*, 346, p. f43.

Sangiorgi, D., and Freire, K. (2010). Service Design & Healthcare Innovation: from consumption to coproduction and co-creation. In *2nd Nordic Service Design Conference, Linkoping*.

Scott, M. (2013). *Community-based services are key to future of NHS*. NHS Trust.

Schifferstein, H. and Hekkert, P. (2008). *Product Experience*. Amsterdam and London: Elsevier Science.

Schrijvers, G., van Hoorn, A. and Huiskes, N. (2012). The care pathway: concepts and theories: an introduction. *International Journal of Integrated Care*, 12, e192.

Schultz, I. Z. and Gatchel, R. J. (2006). *Handbook of complex occupational disability claims: Early risk identification, intervention, and prevention*. Springer Science & Business Media.

Seidel, D., Crilly, N., Langdon, P. M., Matthews, F. E., Jagger, C., Brayne, C. and Clarkson, P. J. (2009). Understanding patterns of capability loss among elderly users. In: *Proceedings of the International Conference on Engineering Design (ICED'09)*. Stanford, USA, 24-27 August 2009, pp. 207-214.

Seidel, D. (2010). Design for independent living activity demands & older people's capabilities. PhD. University of Cambridge.

Semmence, J., Gault, S., Hussain, M., Hall, P., Stanborough, J. and Pickering, E. (1998). *Family Resources Survey, Great Britain 1996-97*. Department of Social Security.

Sen, A. (1992). *Inequality reexamined*. Oxford University Press.

Seymour, J. M., Moore, L., Jolley, C. J., Ward, K., Creasey, J., Steier, J. S., Yung, B., Man, W. D., Hart, N., Polkey, M. I. and Moxham, J. (2010). Outpatient pulmonary rehabilitation following acute exacerbations of COPD. *Thorax*, 65(5), pp. 423-428.

Shaw, C. (2001). *United Kingdom population trends in the 21st century*. Population Trend 103- Office for National Statistics. Government Actuary's Department (GAD).

Shepherd, A. (2001). *Hierarchical Task Analysis.* London: Taylor & Francis.

Sim, J. and Wright, C. (2002). *Research in health care: concepts, designs and methods*. Cheltenham: Stanley Thornes.

Singh, S. J., Zuwallack, R., Garvey, C. and Spruit, M. A. (2013). Learn from the past and create the future: the 2013 ATS/ERS statement on pulmonary rehabilitation. *European Respiratory Journal*, 42, pp. 1169-74.

Smith, J. and Firth, J. (2011). Qualitative data analysis: the framework approach. *Nurse researcher*, 18(2), pp. 52-62.

Stake, R. E. (1995). *The art of case study research*. Sage.

Stanton N.A., Salmon P.M., Rafferty, L.A., Walker, G.H., Baber, C. and Jenkins, D.P. (2005). *Human factors methods: a practical guide for engineering and design*. Aldershot, UK, Ashgate.

Taylor, S., Ellis, I. and Gallagher, M. (2002). Patient satisfaction with a new physiotherapy telephone service for back pain patients. *Physiotherapy*, 88, pp. 645-657.

Terzi, L. (2005). Beyond the Dilemma of Difference: The Capability Approach to Disability and Special Educational Needs. *Journal of Philosophy of Education*, 39(3), pp. 443-459.

Thomas, G. (2011). *How to Do Your Case Study: A guide for students and researchers*. London, Sage.

The Center for Universal Design (1997). *The Principles of Universal Design*. Version 2.0. Raleigh, NC: North Carolina State University."

The Global Language of Business (2018). *Mobile Ready Hero Images Guideline*. Release 1.0, Ratified.

The Kings' Fund (2017). How is the NHS structured?. [online] Available at: https://www.kingsfund.org.uk/audio-video/how-new-nhs-structured

The NHS (2016). *Principles and values that guide the NHS.* The NHS. [online] Available at: https://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx

The NHS Constitution (2013). *Guide to the Healthcare System in England*.

Thorpe, O., Johnston, K. and Kumar, S. (2012). Barriers and enablers to physical activity participation in patients with COPD: a systematic review. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *32*(6), pp. 359-369.

Tight, M. (2017). *Understanding case study research: small-scale research with meaning*. Sage.

United Nations, Department of Economic and Social Affairs, Population Division (2017). *World Population. Ageing 2017 - Highlights (ST/ESA/SER.A/397)*.

UnitingCare Partnership (2015). *Home's Best - providing care closer to home*. [online] Available at: http://www.unitingcare.co.uk/services/homes-best_2.htm. [Accessed: 29 November 2015].

Valentin-Hjorth, J. F., Patou, F., Syhler, N., Vall-Lamora, M. H. D. and Maier, A. (2018). Design for Health: Towards Collaborative Care. In DS92: *Proceedings of the DESIGN 2018 15th International Design Conference*, pp. 2775-2786. DOI: 10.21278/idc.2018.0506

Vanhaecht, K., De Witte, K. and Sermeus, W. (2007). *The impact of clinical pathways on the organisation of care processes*. PhD. Belgium: KU Leuven.

Waller, S. D., Langdon, P. M. and Clarkson, P. J. (2009). Using disability data to estimate design exclusion. *Universal Access in the Information Society*, 9, pp. 195-207.

Waller, S. D., Williams, E. Y., Langdon, P. M. and Clarkson P. J. (2010). Quantifying exclusion for tasks related to product interaction. In: *Designing Inclusive Interactions*, pp. 57-68. London: Springer.

Waller, S. D., Bradley, M. D., Langdon, P. M. and Clarkson, P. J. (2013). Visualising the number of people who cannot perform tasks related to product interactions. *Universal Access in the Information Society*, 12, pp. 263-278.

Waller, S. D., Bradley, M. D., Hosking, I. and Clarkson, P. J. (2015). Making the case for inclusive design. *Applied Ergonomics*, 46, pp. 297-303 [online] Available at: http://dx.doi.org/10.1016/j.apergo.2013.03.012

Warburton, N., Desbarats, G. and Hosking, I. (2013). Developing inclusive design expertise within a client/consultancy relationship. *Applied Ergonomics*, 46(B), pp. 274-278.

Ward, J., Buckle, P. and Clarkson, P.J. (2010). Designing packaging to support the safe use of medicines at home. *Applied Ergonomics*. 41(5), pp. 682-694.

Warren, C. A. B. (2002). 'Qualitative Interviewing', in J. F. Gubrium and J. A. Holstein (eds), *Handbook of Interview Research: Context and Method*. Thousand Oaks, CA: Sage.

Waters, H. R. (2000). Measuring equity in access to health care. *Social Science & Medicine*, 51(4), pp. 599-612.

World Health Organization (2016). *Chronic obstructive pulmonary disease (COPD)*. http://www.who.int/mediacentre/factsheets/fs315/en/ [Accessed 20 May 2016].

Wright, J. (2013). Telephone triage - call the physio. *Frontline*, 19(13).

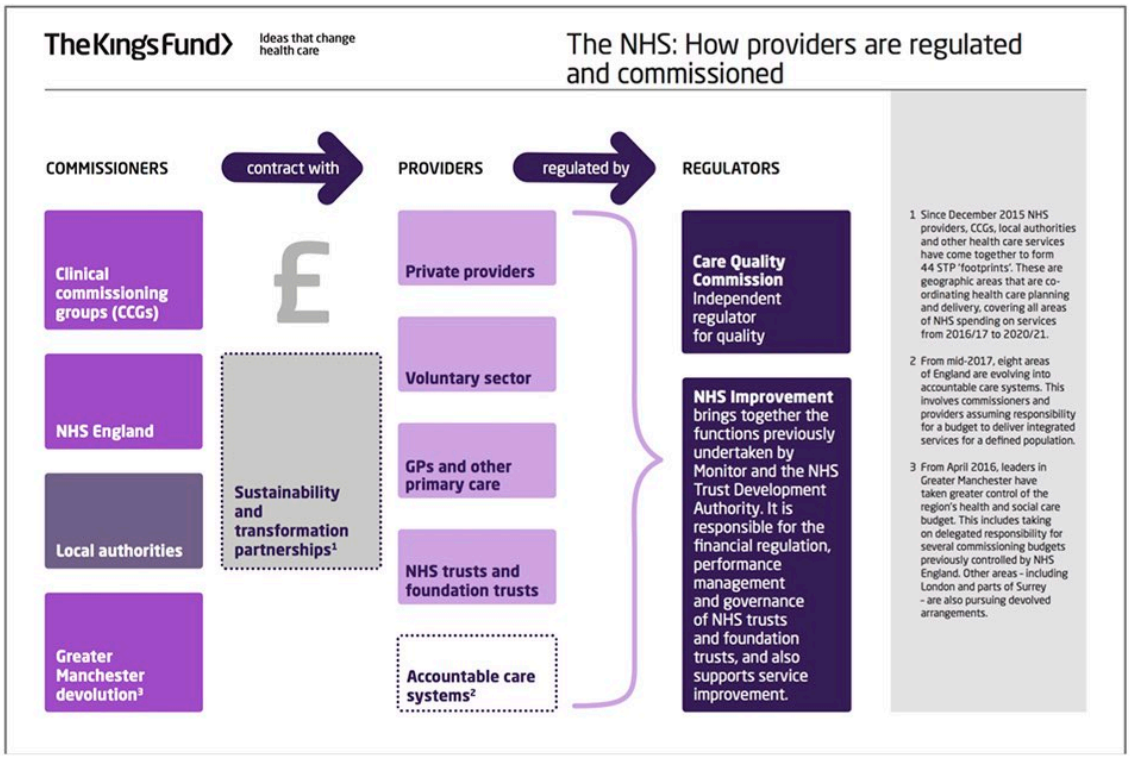
Yawn, B. P. and Wollan, P. C. (2008). Knowledge and attitudes of family physicians coming to COPD continuing medical education. *International Journal of Chronic Obstructive Pulmonary Disease*, 3(2), pp. 311-317.

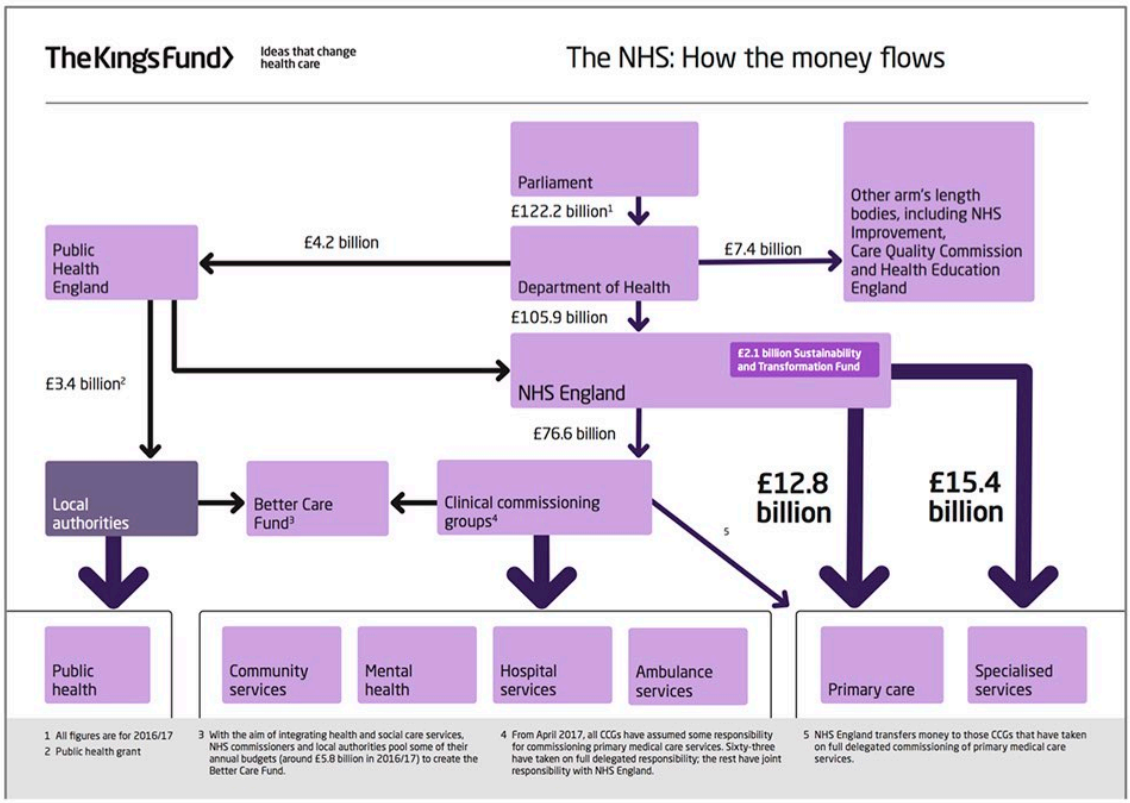
Yin, R. K. (2014). *Case study research: Design and methods.* Los Angeles, CA: Sage.

Yuhas, D. (2017). Forget Pills and Surgery for Back Pain. *Scientific American*. [online] Available at: https://www.scientificamerican.com/article/forget-pills-and-surgery-for-back-pain/ [Accessed October 1, 2017].

Appendices

Appendix A The structure of NHS, summarised by The King's Fund (2017)





Appendix B

Appendix B1: Case study 1- Ethical approval

UNIVERSITY OF CAMBRIDGE
Department of Engineering

Professor Daniel Wolpert
Chairman of the Ethics Review Committee

Miss Yuanyuan Liu
Division C

29 March 2017

Dear Yuanyuan

Ethical Approval for your Research Project: Applying inclusive design to improve people's experience of self-managing back pain in the community

The Department's Research Ethics Committee has considered the documentation you provided in support of your research project in line with recommended procedures concerning ethical approval of research.

I am able to inform you that, with respect to ethical considerations, approval has been given to your project. Please note that this approval is based on the documentation you provided. You must re-submit your application to the Committee should you subsequently make any substantive changes relating to matters reviewed by the Committee.

We are content for this letter to be forwarded to your grant sponsors or to any partner institutions you may be working with if appropriate.

Yours sincerely

Daniel Wolpert

Department of Engineering
University of Cambridge
Trumpington Street
Cambridge CB2 1PZ
research-ethics@eng.cam.ac.uk

Appendix B2: Case study 1 - Online survey

UNIVERSITY OF CAMBRIDGE
Engineering Design Centre

Self-managing back pain

Diagnosing and delivering back pain treatment – what is your professional perspective?

This survey is looking at access to alternative methods of treating back pain in patients, other than face-to-face interventions.

This project has been approved by Research Ethnics Committee of the Department of Engineering University of Cambridge and has been given permission to run within CCS NHST by the Medical Director.

The survey will take less than **4 minutes** to complete. Thank you very much for your time.

For every received valid response, £1 will be donated to the BackCare Charity.

- **SELF-REFERRAL**

Q1. Based on your experience, which of the reasons listed below that may prevent patients accessing back pain treatment by self-referral? (Please select all that apply and add your comments.)

- ☐ Do not know about the service
- ☐ Prefer face-to-face consultation
- ☐ Have difficulty filling in the form
- ☐ Have difficulty sending back the form
- ☐ Other - please add your comments_____

- **TELEPHONE ASSESSMENT**

Q2. Have you ever carried out telephone consultation for back pain patients?

(If yes to question 2 then this one next.)

- ☐ Yes
- ☐ No

Q3. How long does it typically take to assess a patient on the telephone?

- ☐ Less than 10 minutes
- ☐ More than 10 minutes but less than 20 minutes
- ☐ 20-30 minutes
- ☐ Over 30 minutes

Q4. How many years have you worked as a physiotherapist?

- ☐ Less than a year
- ☐ 1-3 years
- ☐ 3-5 years
- ☐ More than 5 years

Q5. Do you think that telephone consultation is a useful way to help back pain patients to access care?

- ☐ Yes
- ☐ No

Q6. What do you think are the benefits of telephone consultation for back pain treatment?
Q7. Why do you think that telephone consultation is NOT useful for back pain patients?
Q8. Do you use any tools or template to help you do the assessment?

- ☐ Yes
- ☐ No

Q9. Please select and add the names of tools or templates that you have used.

- ☐ Physiotherapy self-referral form
- ☐ Startback tool
- ☐ Other - please write the name of the tool_____

1

Appendix B2: Case study 1 - Online survey (continued)

Q10. Which of the following activities do you do during the telephone assessment?

- ☐ Answer the phone
- ☐ Introduce yourself
- ☐ Ask patients' symptoms
- ☐ Measure patients' risk level
- ☐ Provide advice directly
- ☐ Refer patients to face-to-face physiotherapists
- ☐ Refer patients to further checks with specialists
- ☐ Other_____

Q11. Do you experience any difficulties when you talk with patients and provide care over the phone?

- ☐ Yes
- ☐ No

Q12. Please select the difficulties you encounter when talking with patients over the telephone.

(Please select all that apply and add your comments.)

- ☐ I cannot hear patients' words
- ☐ I cannot understand patients' words
- ☐ It is difficult to establish rapport with patients
- ☐ It adds to my workload and is impersonal talking over the phone
- ☐ Other - please add your comments_____

Q13. What difficulties do you think patients may have when accessing treatment over the telephone?

(Please select all that apply and add your comments.)

- ☐ Patients cannot hear me properly
- ☐ Patients cannot understand me properly
- ☐ Patients cannot describe their symptoms to me clearly
- ☐ Patients have to wait for a long time to call in
- ☐ Other - please add your comments_____

- **GP SERVICES**

Q14. When a referral from GP practices, what information do you receive from GPs?

(Please select all that apply and add your comments.)

- ☐ GP referral letter
- ☐ Patients' basic information through the electronic system
- ☐ A brief description of Patients' symptoms
- ☐ Not receiving information from GPs
- ☐ Other - please add your comments_____

- **OTHERS**

Q15. Besides self-referral, telephone assessment and visiting GPs, is there any other pathway by which back pain patients can access treatment?

- ☐ Yes. Please add your comments_____
- ☐ No

Q16. Are you willing to participate a further interview? It will last about 20-30mins, and can be face-to-face, at a location of your choice, or via the telephone.

- ☐ Yes. Please leave your contact information_____
- ☐ No

Thank you very much for your time. A summary of the project will be shared at the end of the study.

2

Appendix B3: Case study 1 - Schedule of interviewing physiotherapists

UNIVERSITY OF CAMBRIDGE
Engineering Design Centre

Schedule of Interviewing physiotherapists

1. Objective of the interview:

The purpose of this interview is to understand healthcare professionals' perceptions and experiences of the care pathways for back pain treatment. Healthcare professionals are encouraged to share their experiences of providing back pain treatment.

2. Interview facilitator:

Yuanyuan Liu: A PhD Candidate in the Engineering Design Centre at the Engineering Department of the University of Cambridge. This project is one part of her PhD project.

3. Opening

- Introduction:

Good Morning/ Afternoon. My name is Yuanyuan Liu. I am a PhD student from the University of Cambridge. Thank you very much for agreeing to have an interview.

- Questions for icebreaker:
  - What is your name?
  - How are you today?
  - Are you happy to start?
  - How long have you been working here?
  - Could you possibly tell me a bit about your background and your role here?

- What is the research about?

There are three ways that patients can receive back pain treatments: self-referral, telephone assessment by physiotherapists and GP visits. Telephone assessment is the most cost-effective as low-risk patients can be self-managed with advice and often require no further intervention. My research will focus on increasing the use of telephone assessment and reducing patients' need to visit their GP. I will look at patients' back pain self-care journey, from how patients know the care treatment options to how they access these services. My research will focus on identifying barriers that affect patients' access to proper self-management, in particular those barriers that are caused by not taking into account the reduced capabilities (including vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) of people with back pain. This will inform ways to increase the number of people engaged in telephone-based back pain management.

The main question we want to explore in this research is:

How can design be used to improve people's experience of self-managing their back pain?

4. Main

At this point, I am interested in learning from your actual experience of providing care as a physiotherapist.

1

Appendix B3: Case study 1 - schedule of interviewing physiotherapists (continued)

Telephone assessment:

- How many telephone assessments on average do you do per day?
- What do you think of telephone assessment in terms of helping back pain patients access care?
- Are there any procedures that you follow to diagnose a patient?
- Could you please recall those telephone assessments you did during the last three months and share with me the one that stood out for you? For example, the one that you or the patients have some difficulties during the telephone assessment?
- What difficulties do you encounter when talking with patients over the telephone?
- Probes: Could you tell me more about------?
- What difficulties do you think patients may have when accessing treatment via the telephone?
- Probes: Could you tell me more about------?
- Are there some physical disability like their vision will affect them to access the telephone assessment? How about hearing/ thinking/ communication/ dexterity/ reach and stretch?
- Could you please help me check the accuracy of this procedure that patients may go through when they access telephone assessment?
- Probes: show the map to the interviewees (the map has been drawn after finishing the survey)

Self-referral:

- How do patients self-refer? What is the detailed process for patients engaging in self-referral, such as how do they obtain the self-referral form and where do they submit the form?
  Probes: Could you tell me more about------?

GP services:

- Can you describe the procedures as to how a GP would refer a patient? How do you share patients' data?
  Probes: Could you tell me more about------?

Others:

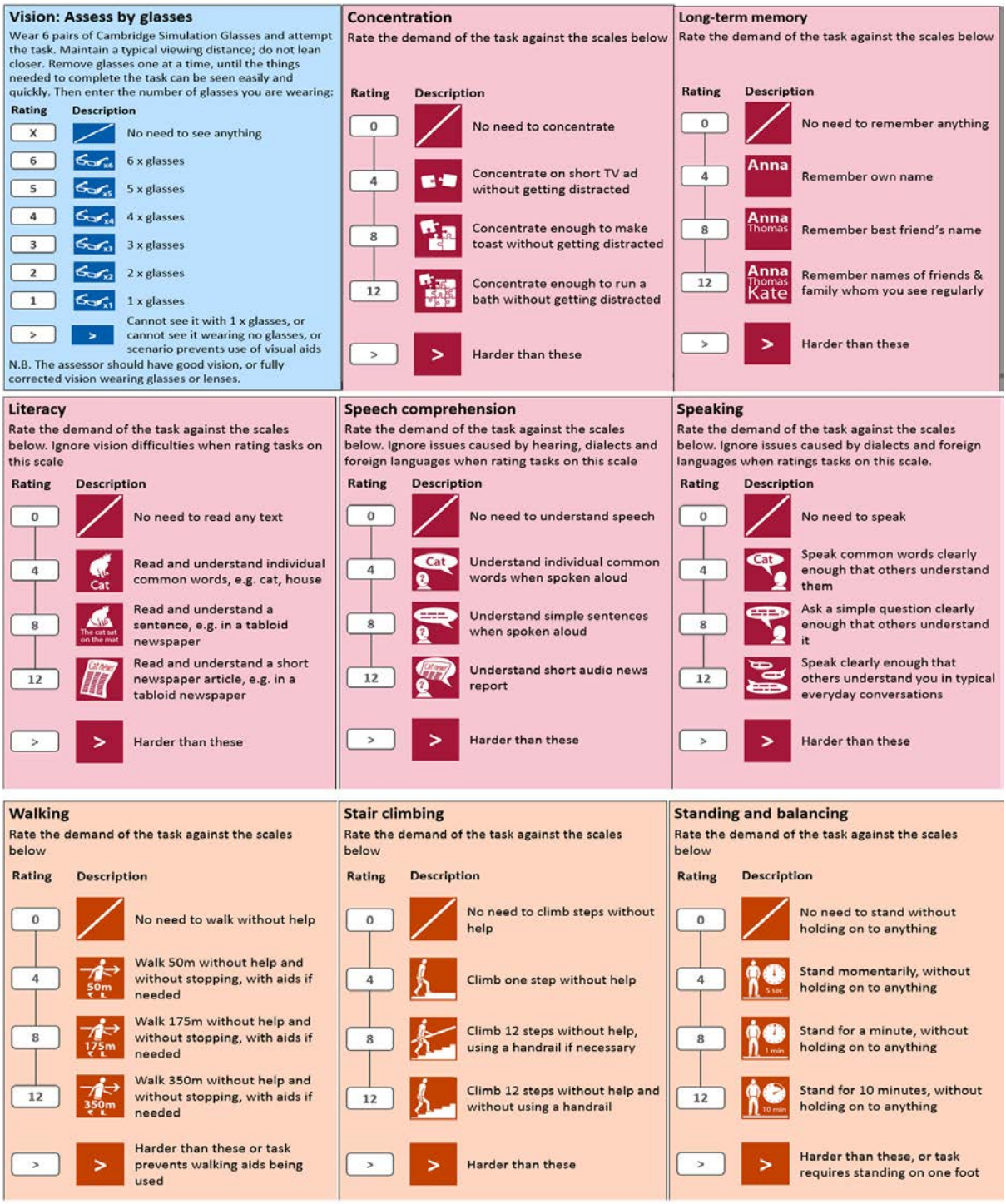
- Are there other professionals with whom you have to work? Can you describe what do they do for you?
- Is there any data available to show the frequency of use among the three treatment options: self-referral, telephone assessment, and visiting GPs?

5. Closing

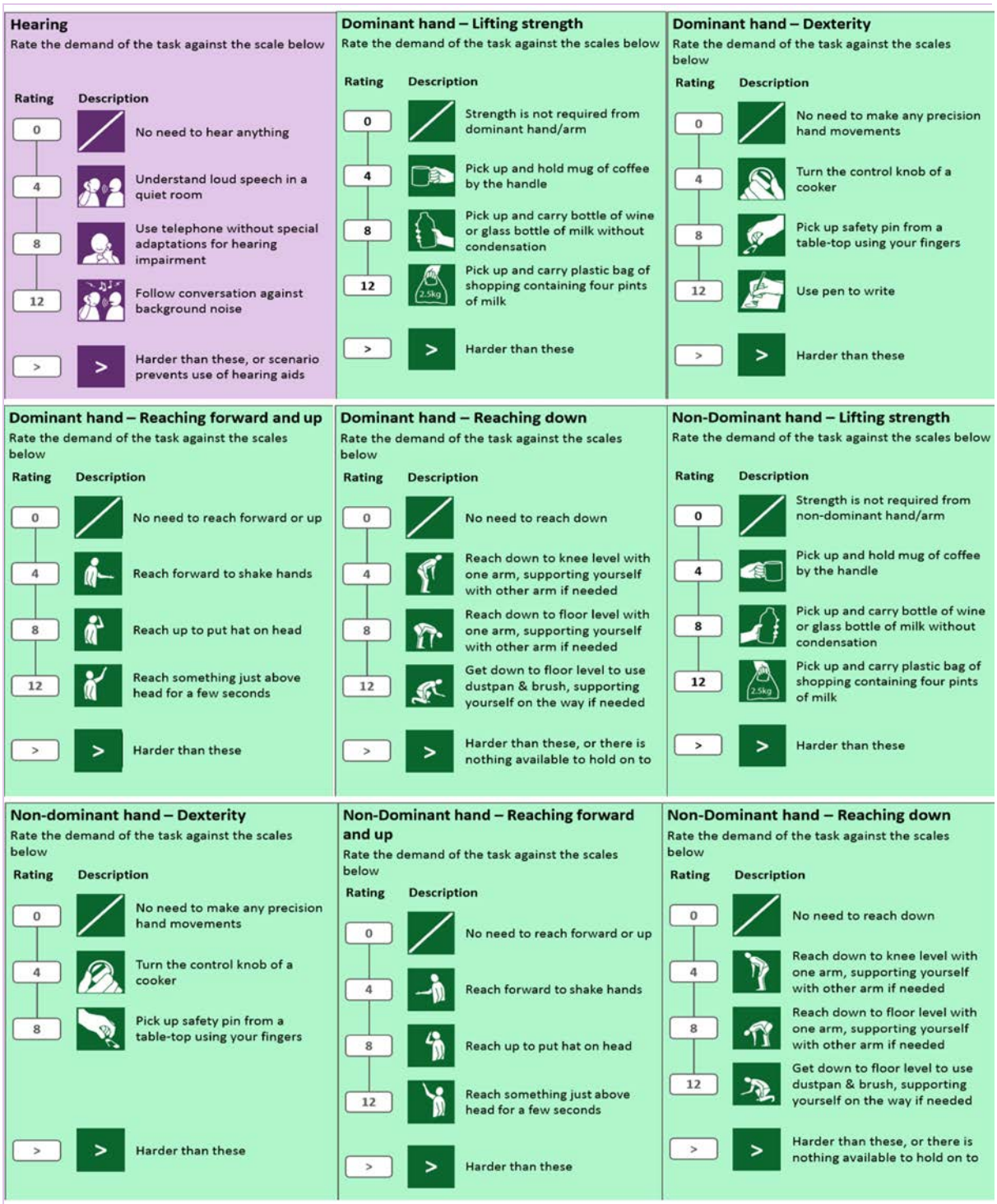
Thank you very much for your time. Your answers are very helpful. Are there any questions you would like to ask me? Thank you so much.

2

Appendix B4: The pre-defined (demand measure) scales



Appendix B4: The pre-defined (demand measure) scales (continued)



Appendix C

Appendix C1: Ethical approval for case study 2 (COPD)

NHS
Health Research Authority

Dr Jonathan Fuld
Consultant Physician
Cambridge University Hospital NHS Trust
Box 40
Hills Road
Cambridge
CB2 0QQ

Email: hra.approval@nhs.net

24 April 2017

Dear Dr Fuld,

Letter of HRA Approval

Study title:	**Improving the utilisation of pulmonary rehabilitation through development of a toolkit for use by referring clinicians and enhancing the inclusivity of the pulmonary rehabilitation pathway**
IRAS project ID:	**209597**
REC reference:	**17/EE/0136**
Sponsor	**Cambridge University Hospital NHS Foundation Trust**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Appendix C2: Case study 2 - Schedule of interviewing HCPs (Version 1)

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS NHS Foundation Trust

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Schedule of Interviewing Healthcare Professionals

- **Objective of interview:**

The purpose of this interview is to understand healthcare professionals' perceptions and experiences of the pulmonary rehabilitation pathway. Healthcare professionals will be encouraged to share their experiences of providing pulmonary rehabilitation.

- **Interview facilitator:**

Yuanyuan Liu: A PhD Candidate in the Engineering Design Centre at the Engineering Department of the University of Cambridge. This project is one part of her PhD project.

- **Opening (about 2-3mins)**

- Introduction:

Good Morning/ Afternoon. My name is Yuanyuan Liu. I am a PhD student from the University of Cambridge. Thank you very much for agreeing to have an interview.

- Questions for icebreaker:
  - What is your name?
  - How are you today?
  - Are you happy to start?
  - How long have you been working here?
  - Could you possibly tell me a bit about your background and your role here?

- What is the research about?

Pulmonary rehabilitation (PR) is claimed to be one of the most effective methods of treating people with COPD. However, despite the evidence of effectiveness, many people diagnosed with COPD do not accept a PR offer due to poor treatment access. The aim of this research is to ensure that as many people with COPD as possible enter PR by identifying barriers to access. In particular, those barriers are caused by not taking into account the reduced capabilities (including vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) of people with COPD.

The main question we want to explore in this research is:
How can inclusive design principles be used to improve people's experience of accesssing pulmonary rehabilitation within the community?

- **Body (about 20-25 mins)**

At this point, I am interested in learning from your actual experience of providing care as a GP, practice nurse, physiotherapist or manager.

Appendix C2: Case study 2 - Schedule of interviewing HCPs (Version 1) (continued)

Questions for interview

- **PR pathway of Healthcare professionals:**

First, I would like to explain the concept of a care pathway. A care pathway refers to the process that people go through in order to receive care. I can give you a similar example, i.e., eating. If you would like to have a dinner in a very popular restaurant, you may need to book in advance. Once you have booked, some factors such as the traffic and location will affect whether or not you arrive on time. During the meal, the service of the waiters, the atmosphere and, of course, the food will all affect your eating experience. After the meal, you will judge the experience in your own way. The booking, the journey to the restaurant and the eating process as a whole is similar to patients' access to a healthcare service, but the former scenario is the pathway for eating.

Then I will show a picture that illustrates the primary care PR pathway to the interviewee and I will ask the following questions:

- Looking at the picture, do you agree with this pathway of COPD? Is there any difference in the pathway you have experienced?
  Probes: Can you describe a more detailed care pathway of PR? I am interested in all the professionals that are involved, i.e., what they do for the people with COPD and the information they need.

- What is your main role along the primary care pulmonary rehabilitation (PR) pathway?
  Probes: what other professionals do you have to work with? Can you describe what they do for you?

- What information do you expect to receive from other professionals you work with?
  What information will you pass to the next stage's healthcare professionals?
  Probes: Could you tell me more about------?

- Does the COPD patient have some knowledge about the PR pathway? / Do they know where they can get support?
  Probes: Could you tell me more about------?

- Can you recall the last time you talked with a new patient with COPD? Can you describe what you did for him or her? Perhaps it may be useful to think of how things happened along the care pathway. How did you feel at that moment?
  Probes: Could you tell me more about------?

- **Perception and experience of Pulmonary rehabilitation service:**
- From your perspective, what is the purpose of pulmonary rehabilitation?
  Probes: Can you tell me more about------?

- Can you recall a person with COPD who was reluctant to take up PR? What factors do you think affected his/ her uptake and attendance?
  What factors do you think may affect people's uptake and attendance of the PR pathway?

2

Appendix C2: Case study 2 - Schedule of interviewing HCPs (Version 1) (continued)

Probes: Which (three) factors do you think are most important?

- Do you know someone who declined PR because they think the course does not provide what they need?
  Probes: Could you tell me more about------?

- How do you know whether or not a patient who took up the PR programme or quit at a later stage?
  Probes: How do you communicate with your patients? What information do you expect your patients to tell you? What information do you convey to the patients?

- Does PR always work? Can it be further improved?
  Probes: Could you tell me more about------?

- **The relationship between capabilities and accessibility**
- Do you think there are any connections between people's personal capabilities (physical and cognitive abilities) and their uptake and attendance of PR?

- For those people who cannot access pulmonary rehabilitation (any stage of the pathway), do you think it is because they cannot go to the rehab centre or they cannot do the exercise within PR?

- Do people give up PR because they think their capabilities are not sufficient to manage the PR programme?
  Probes: Can you tell me more about------?

- **Closing (about 2mins)**

Thank you very much for your time. Your answers are very helpful. Are there any questions you would like to ask me? I may contact you for further information. Thank you so much.

- **Others**

The overall interview time will last about 30mins.

3

Appendix C3: Case study 2 - Schedule of interviewing HCPs (Version 2)

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Schedule of Interviewing Healthcare Professionals

- **Introduction:**

Good Morning/ Afternoon. My name is Yuanyuan (Daisy) Liu. I am a PhD student from the University of Cambridge. Thank you very much for agreeing to have an interview.
Questions for icebreaker:

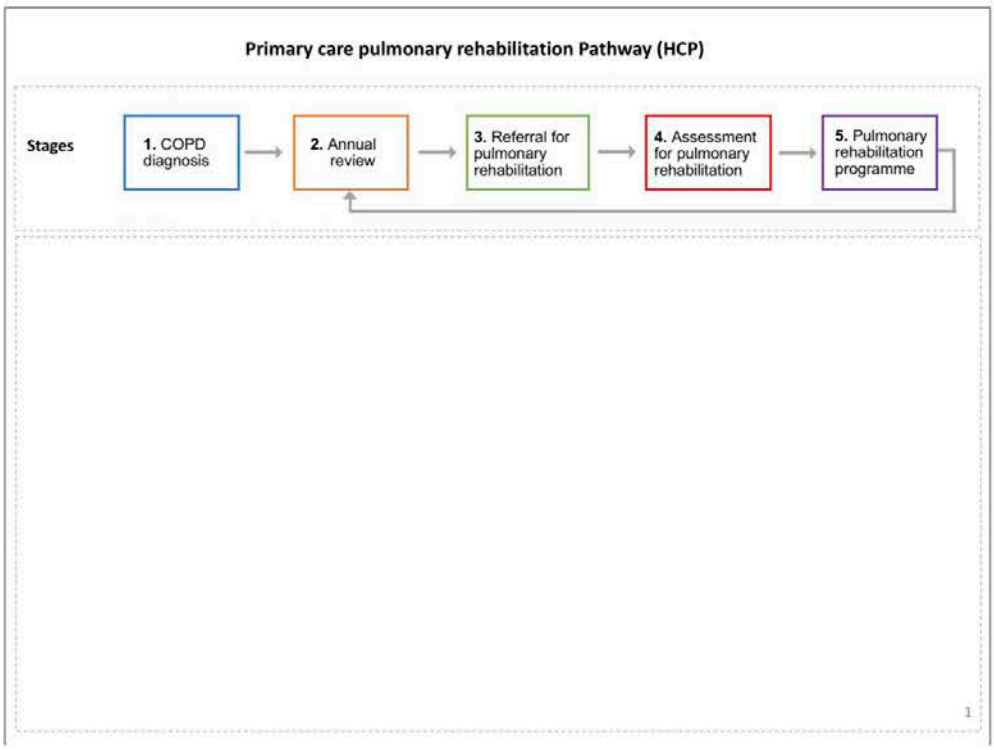
- What is your name?
- How are you today?
- Are you happy to start?
- How long have you been working here?
- Could you possibly tell me a bit about your background and your role here?

- **Care pathway/ journey**

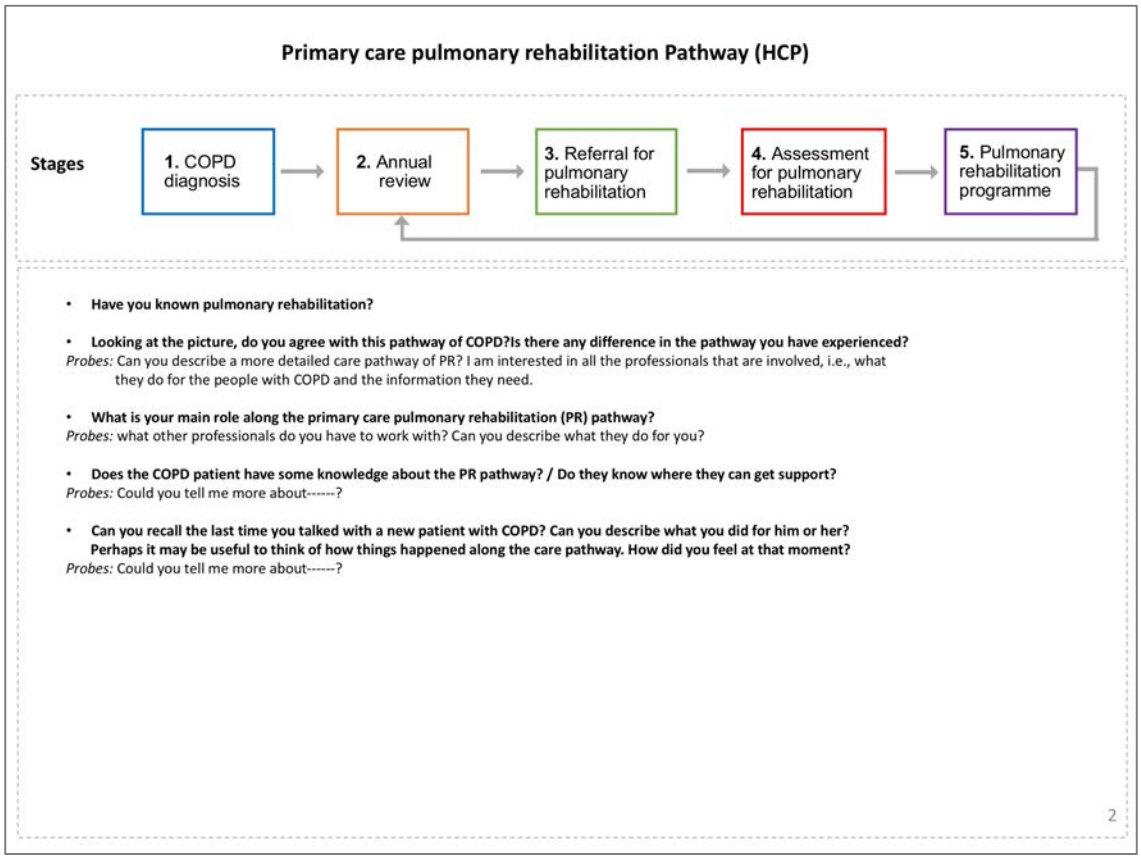
- Do you use this word pathway/ journey during your working?
- Which word (pathway or journey) do you more familiar with? Why?

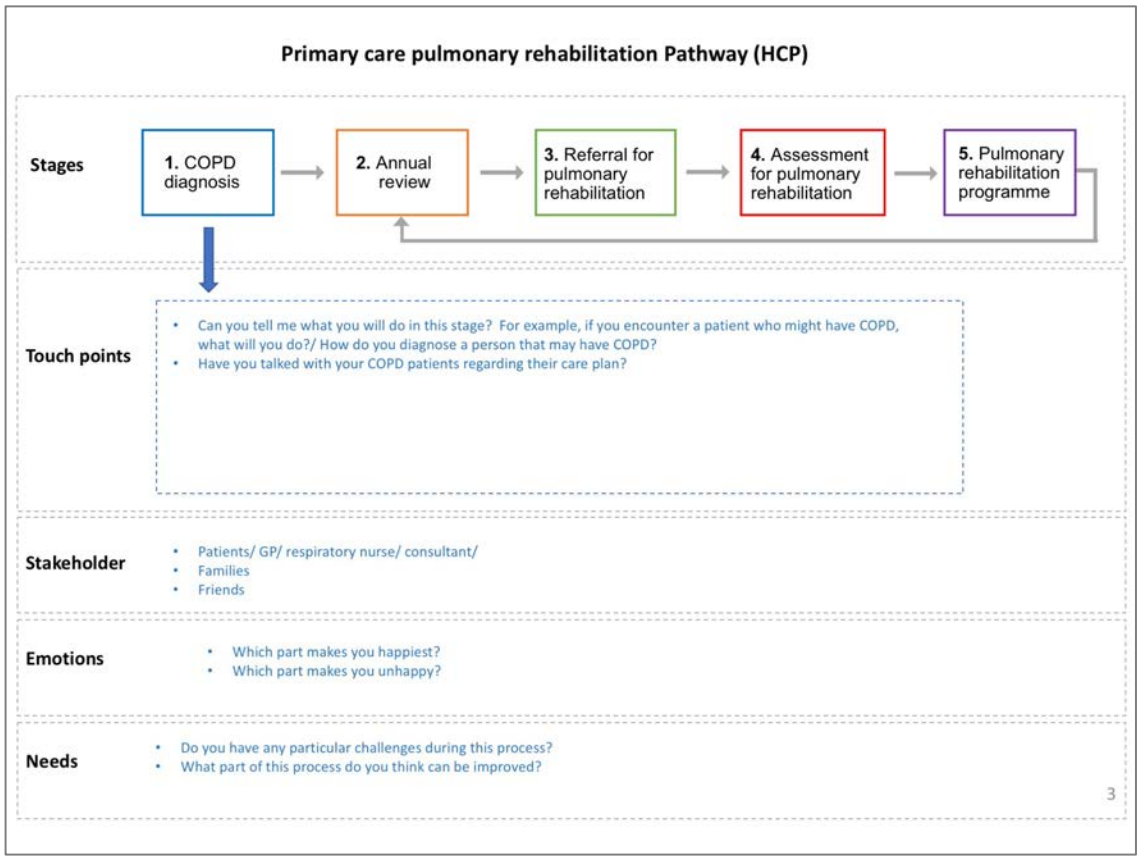
A care pathway/journey refers to the process that people go through in order to receive/ deliver care. I can give you a similar example, i.e., eating. If you would like to have a dinner in a very popular restaurant, you will go through the booking, the journey goes to the restaurant eating and go back. The whole process we call it journey, so some people prefer to say patient's journey, but some people prefer care pathway from medical perspective.

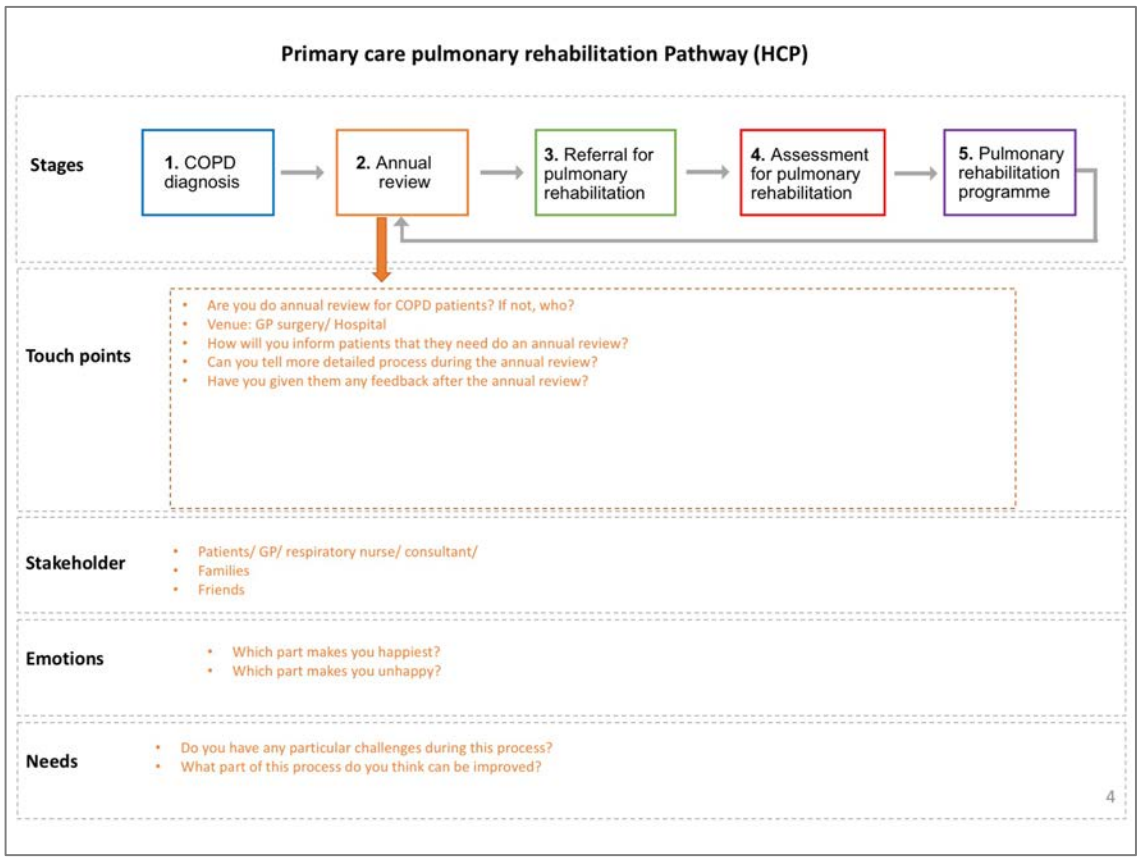
Then the following 7 cards are used to guide the interview. The closing part is the same as the version 1 in appendix 6.

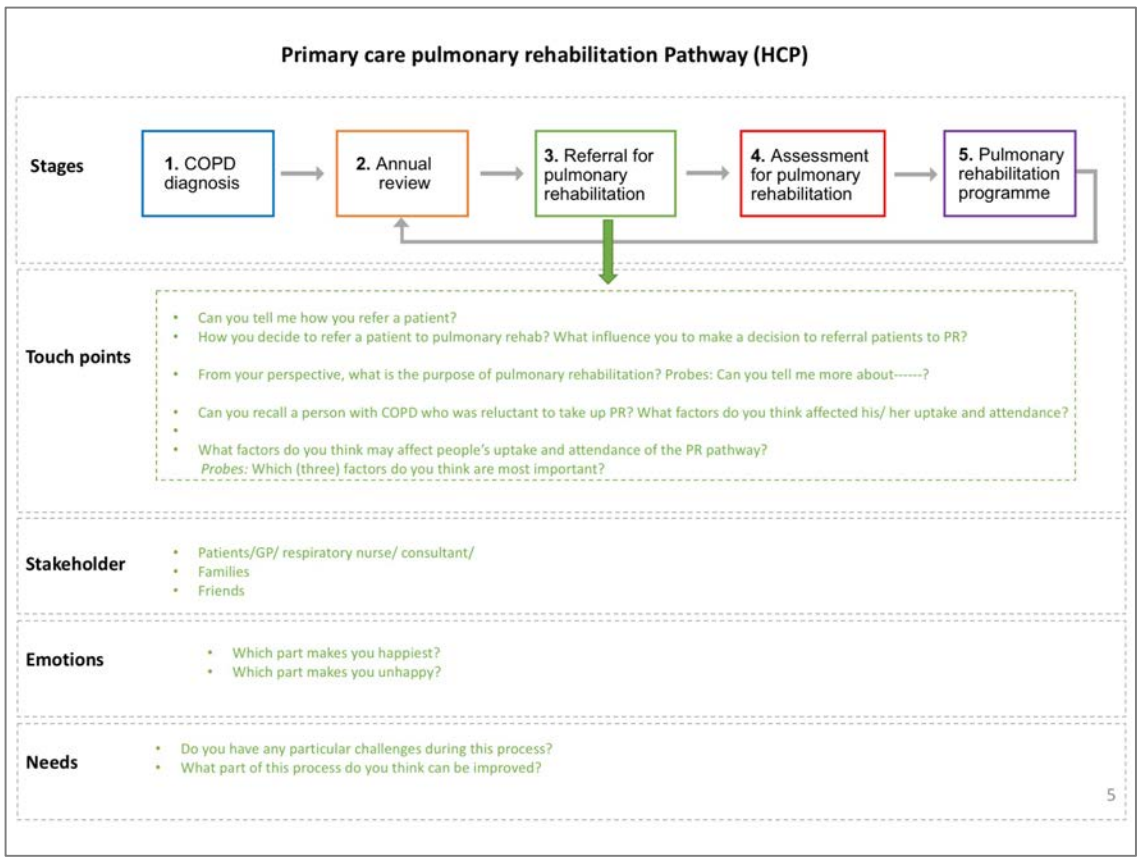


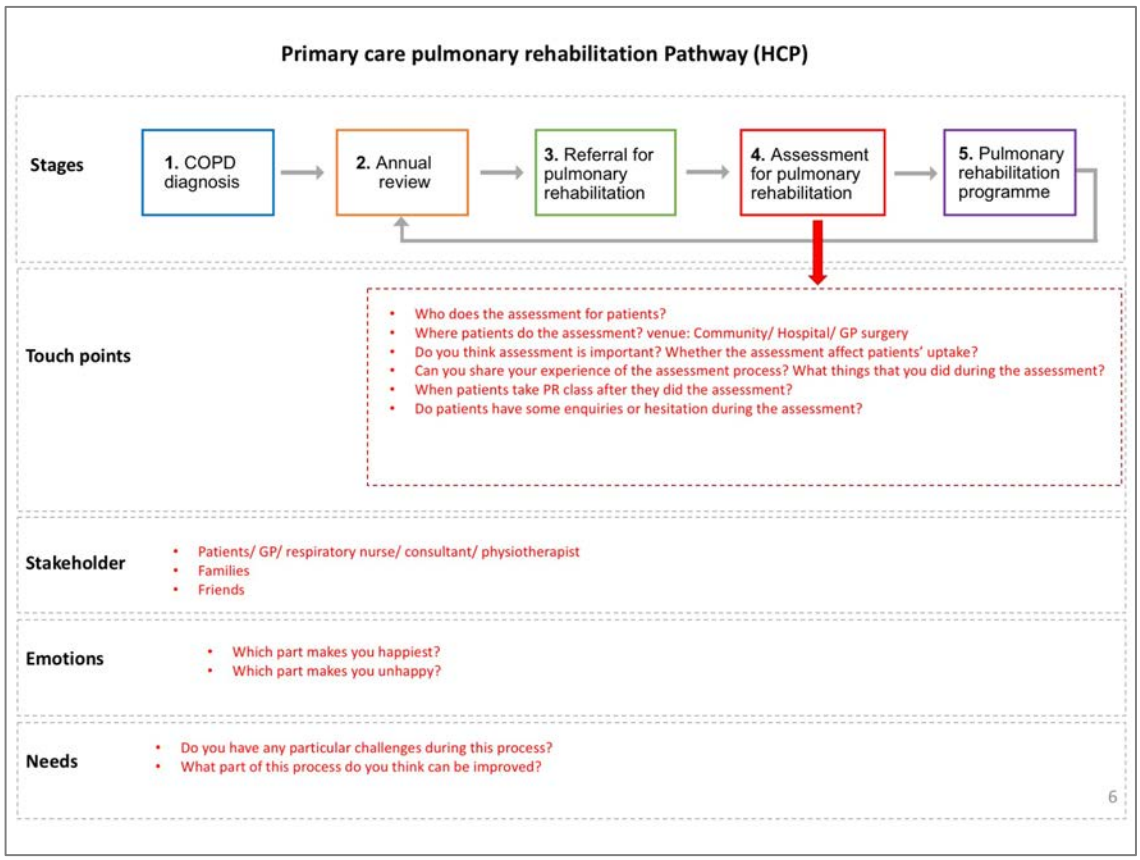
Appendix C3: Case study 2 - Schedule of interviewing HCPs (Version 2) (continued)

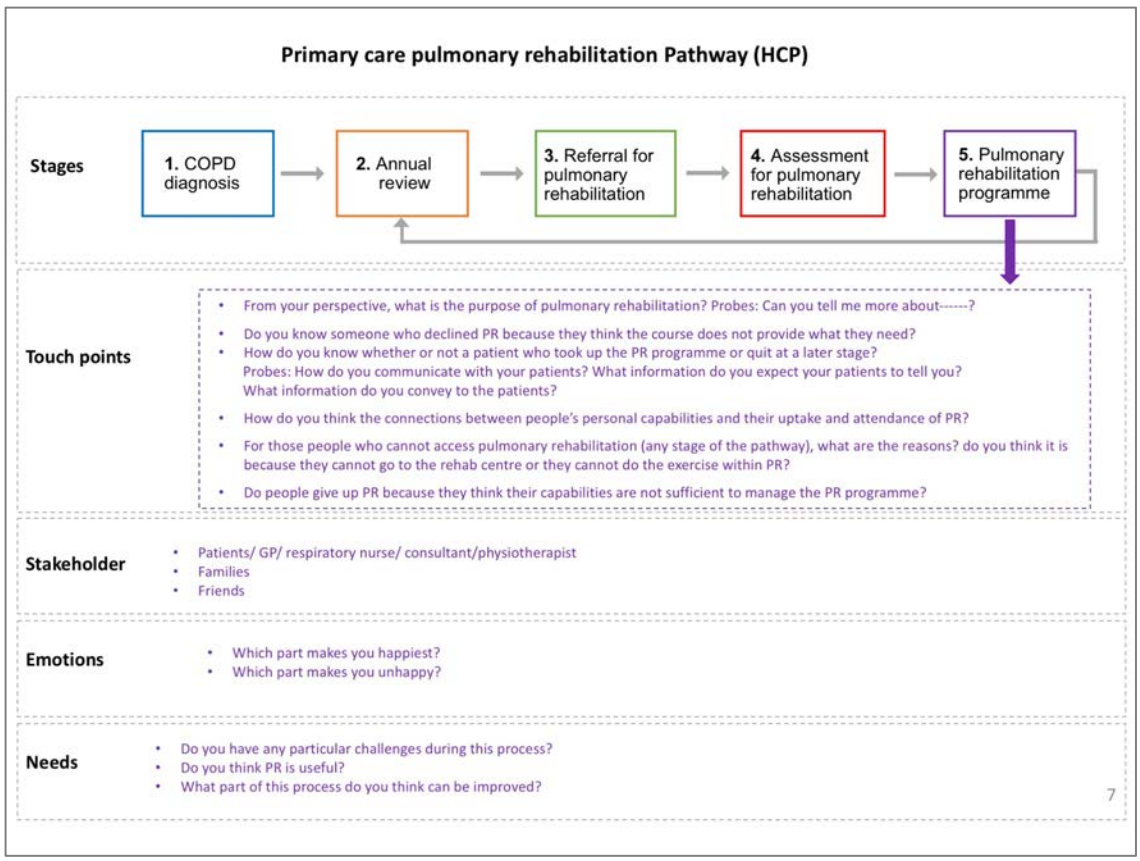





Primary care pulmonary rehabilitation Pathway (HCP)
Stages
1. COPD diagnosis
2. Annual review
3. Referral for pulmonary rehabilitation
4. Assessment for pulmonary rehabilitation
5. Pulmonary rehabilitation programme
Touch points
Are you do annual review for COPD patients? If not, who?
Venue: GP surgery/ Hospital
How will you inform patients that they need do an annual review?
Can you tell more detailed process during the annual review?
Have you given them any feedback after the annual review?
Stakeholder
Patients/ GP/ respiratory nurse/ consultant/
Families
Friends
Emotions
Which part makes you happiest?
Which part makes you unhappy?
Needs
Do you have any particular challenges during this process?
What part of this process do you think can be improved?
4


Primary care pulmonary rehabilitation Pathway (HCP)
Stages
1. COPD diagnosis
2. Annual review
3. Referral for pulmonary rehabilitation
4. Assessment for pulmonary rehabilitation
5. Pulmonary rehabilitation programme
Touch points
Can you tell me how you refer a patient?
How you decide to refer a patient to pulmonary rehab? What influence you to make a decision to referral patients to PR?
From your perspective, what is the purpose of pulmonary rehabilitation? Probes: Can you tell me more about------?
Can you recall a person with COPD who was reluctant to take up PR? What factors do you think affected his/ her uptake and attendance?
What factors do you think may affect people's uptake and attendance of the PR pathway?
Probes: Which (three) factors do you think are most important?
Stakeholder
Patients/GP/ respiratory nurse/ consultant/
Families
Friends
Emotions
Which part makes you happiest?
Which part makes you unhappy?
Needs
Do you have any particular challenges during this process?
What part of this process do you think can be improved?
5


Primary care pulmonary rehabilitation Pathway (HCP)
Stages
1. COPD diagnosis
2. Annual review
3. Referral for pulmonary rehabilitation
4. Assessment for pulmonary rehabilitation
5. Pulmonary rehabilitation programme
Touch points
Who does the assessment for patients?
Where patients do the assessment? venue: Community/ Hospital/ GP surgery
Do you think assessment is important? Whether the assessment affect patients' uptake?
Can you share your experience of the assessment process? What things that you did during the assessment?
When patients take PR class after they did the assessment?
Do patients have some enquiries or hesitation during the assessment?
Stakeholder
Patients/ GP/ respiratory nurse/ consultant/ physiotherapist
Families
Friends
Emotions
Which part makes you happiest?
Which part makes you unhappy?
Needs
Do you have any particular challenges during this process?
What part of this process do you think can be improved?
6


Primary care pulmonary rehabilitation Pathway (HCP)
Stages
1. COPD diagnosis
2. Annual review
3. Referral for pulmonary rehabilitation
4. Assessment for pulmonary rehabilitation
5. Pulmonary rehabilitation programme
Touch points
From your perspective, what is the purpose of pulmonary rehabilitation? Probes: Can you tell me more about------?
Do you know someone who declined PR because they think the course does not provide what they need?
How do you know whether or not a patient who took up the PR programme or quit at a later stage?
Probes: How do you communicate with your patients? What information do you expect your patients to tell you?
What information do you convey to the patients?
How do you think the connections between people's personal capabilities and their uptake and attendance of PR?
For those people who cannot access pulmonary rehabilitation (any stage of the pathway), what are the reasons? do you think it is because they cannot go to the rehab centre or they cannot do the exercise within PR?
Do people give up PR because they think their capabilities are not sufficient to manage the PR programme?
Stakeholder
Patients/ GP/ respiratory nurse/ consultant/physiotherapist
Families
Friends
Emotions
Which part makes you happiest?
Which part makes you unhappy?
Needs
Do you have any particular challenges during this process?
Do you think PR is useful?
What part of this process do you think can be improved?
7

Appendix C4: Case study 2 - Invitation letter for interviewing HCPs

Introductory email from Researcher and Study GP to HCPs to take part in interviews

Dear < name >,
Improving referral and uptake to pulmonary rehabilitation (PR) for people living with COPD

I am writing to invite you to take part in a PhD research study that aims to increase the number of people with COPD who may benefit from pulmonary rehabilitation. This is in line with the National COPD Audit Programme which highlighted low rates of referral and uptake across England and Wales in 2013/14 and significant clinical benefit from pulmonary rehabilitation. Please find attached an information sheet (version n) that outlines the study.

I would like to invite you to take part in a short interview (about 20-30mins) to explore your views and experiences of delivering COPD care, for example how you make the decision to refer people to the PR programme and how patients take up the PR programme. Please let me know if you are able to take part by replying to this email or contacting me on the details below. I will be happy to arrange a date, time and venue that are convenient for you.

Please don't hesitate to contact me if you have any queries.
Thank you very much and look forward to your reply.

Best wishes,
Yuanyuan Liu

Email: yl528@cam.ac.uk
Tel: 07922281772 (anytime) or 01223 748577 (8.30-18.00)

Appendix C5: Case study 2 - Lay summary

Improving Utilisation of PR - WP1: Lay summary Version 1. 10th Jan 2017

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Improving people's experience of accessing pulmonary rehabilitation (PR)

I would like to increase the number of people with long term lung disease who benefit from a treatment called pulmonary rehabilitation (PR) by identifying barriers that prevent their access to this programme.

Background

Approximately 1.2 million people in the UK have Chronic Obstructive Pulmonary Disease (COPD) causing breathlessness, difficulty with daily activities, frequent infections and hospitalisation. Pulmonary rehabilitation (PR), providing supervised exercise and advice to help control symptoms, improves quality of life and avoids hospital admissions. Some people with COPD do not receive PR because either healthcare professionals do not refer them or they do not know about it. Of those referred 31% do not take up the offer. There are no well-proven solutions that increase the number of people attending PR.

There are two ways to increase the number of people with COPD who may benefit from PR: one is to improve referral rate for PR, the other is to increase people's opportunity to take up the programme. My research is focused on both. It will look at the whole COPD care journey including the process of diagnosis, annual review, referral to PR, assessment for PR, accessing to and after finishing PR to ensure maximised number of people access to PR. Specifically, it will focus on identifying barriers that affect the referral and uptake process. In particular, those barriers are caused by not taking into account the reduced capabilities (including vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) of people with COPD. This will inform ways to increase the number of people accessing PR.

Proposed research

- We will interview healthcare professionals to gather insight into their experiences of delivering COPD care, for example how healthcare professionals make the decision to refer people to the PR programme.
- We will also interview people with COPD to gather insight into their experience of receiving COPD treatment, for example which things they find easy or difficult in order to access the PR service.
- We will endeavour to understand the challenges caused by access to PR for individuals and estimate how many people who were initially referred to PR might be unable to access the service.
- Our results will be summarised and shared with care providers to enable them to better understand needs of patients and the barriers to uptake of the PR programme.

Contact Information:

Yuanyuan(Daisy) Liu, PhD candidate, University of Cambridge Email: yl528@cam.ac.uk

Appendix C6: Case study 2 - Participant Information Sheet for interviewing HCPs

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Interview Participant Information Sheet for Healthcare Professionals

IRAS Number: 209597

Short title: Improving utilisation of pulmonary rehabilitation-WP1

Full research title: Applying inclusive design to improve people's experience of accessing pulmonary rehabilitation (PR) within the community

We would like to invite you to participate in the *improving utilisation of pulmonary rehabilitation* research project. It is important that you understand what this research is about and what it will involve. This will help you decide whether or not to take part. Please take your time to read the following information carefully. If you have any questions about this study, please contact us using the contact details below. Your participation is **entirely voluntary**.

1. What is the purpose of this research study?

Approximately 1.2 million people in the UK have Chronic Obstructive Pulmonary Disease (COPD) causing breathlessness, difficulty with daily activities, frequent infections and hospitalisation. Pulmonary rehabilitation (PR), provides supervised exercise and advice to help control symptoms, improves quality of life and avoids hospitals admissions. Some people with COPD do not receive PR because either healthcare professionals do not refer them or they do not know about it. Of those referred 31% do not take up the offer. There are no well-proven solutions that increase the number of people attending PR.

There are two ways to increase the number of people with COPD who may benefit from PR: one is to improve the referral rate for PR, the other is to increase people's opportunity to take up the programme. My research is focused on both. It will look at the whole COPD care journey including the process of diagnosis, annual review, referral to PR, assessment for PR, access to and after finishing PR to ensure the maximum number of people access to PR. Specifically, it will focus on identifying barriers that affect the referral and uptake process. In particular, those barriers are caused by not taking into account the reduced capabilities (including vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) of people with COPD. This will inform ways to increase the number of people accessing PR.

2. Who can take part in this research study?

You can take part if:

- You are a GP, a practice nurse, a physiotherapist, a commissioner, or a service manager knowing the healthcare services available to people with COPD.
- You are happy to share your experience of referring people to PR or providing PR.

3. Why are we approaching you?

We need your help with this work because you have valuable insights and experience of providing healthcare or contributing to the provision of healthcare services to those people with COPD. Your first-hand feedback is of utmost importance to us.

Appendix C6: Case study 2 - Participant Information Sheet for interviewing HCPs (continued)

4. Do you have to take part?
NO. It is up to you to decide whether or not to take part. If you agree to participate, you will be given this information sheet to keep and be asked to sign a consent form.

5. How can you take part?
An interview will take place, face to face in your office, or by phone, and it will take approximately 30 minutes. We will focus on your experiences and understanding of how services are delivered. If you give permission, interviews will be audio recorded. Alternatively, the researcher will take notes. Data will be transcribed and stored anonymously and securely.

6. Can you withdraw from the project at any stage?
YES. If you decide not to take part after you have signed a consent form, this will not affect you in any way and there will be no consequences for your work. If you withdraw from the project at any stage, you do not need to give a reason and any of the information you have already contributed until that point will remain part of the project.

7. Will my taking part in this project be kept confidential?
YES. All data collected in this study will be kept confidential and cannot be traced back to you. No participant will be identified by name or organisation in any publication. Direct quotations will be used in PhD thesis and publications but these will be completely anonymised and cannot be identified with any individual. The data collected will only be accessible to the research team. The audio recording of the interviews will be stored on a secure computer, in a restricted-access server at the Engineering Department of the University of Cambridge. Only the research group has access to this information and the protocols for protecting confidentiality are very strict. On completion of the study, all information held would be stored in a secure place and destroyed after 5 years.

8. What will happen to the information you provide?
Information collected from participants in this project will help to understand healthcare professionals' perceptions and experiences of the pulmonary rehabilitation. The data will also help to understand people's care needs when they access to pulmonary rehabilitation.

9. What are the possible benefits of taking part?
Your contribution will be valuable. The findings will provide researchers with a better understanding on care staff's perception and experience of COPD care. It may also help participants to rethink COPD care, which in turn may help to provide further understanding of patients' needs. The participants will be remunerated for transport. Research findings will be shared if requested.

10. What are the possible disadvantages and risks of taking part?
There are no disadvantages or risks in taking part in this interview, other than the time it will take to collect your responses.

2

Appendix C6: Case study 2 - Participant Information Sheet for interviewing HCPs (continued)

11. How will the findings be used?

The findings of this study will be will be presented in the researcher's PhD thesis. It may also be presented at conferences and written up in journals, so that it will help care providers understand the needs of people with COPD. The results may also help develop an intervention to increase the uptake of PR. A lay summary of the findings will be sent to you if you wish.

12. How has this study been funded?

This research is a PhD research project, and the researcher is funded by the China Scholarships Council (CSC). The funding provided by CSC covers the researcher's tuition and living expenses in the University of Cambridge.

13. What happens now?

If you decide to take part in this research project, please let us know by sending an email to yl528@cam.ac.uk or calling to 01223 748 577 or texting to 07922 281 772. Please let us have details of your address, phone or email address to enable us to discuss when and where the interview will take place. If you decide not to continue taking part at any point, just let us know and you do not need to do anything more. We will remove your contact details from the project.

Further information

Thank you very much for your time. Please keep this information sheet in a safe place. If you need more information, please text or call at the dedicated research mobile: 07922 281 772

Research Team:

Researcher: Yuanyuan Liu, PhD candidate, Department of Engineering, University of Cambridge.
Supervisors: Professor P John Clarkson, Director of EDC, University of Cambridge;
Dr. Terry Dickerson, Senior Research Associate, University of Cambridge.
Collaborators: Jonathan Fuld, Consultant Physician, Cambridge University Hospitals;
Frances Early, Centre for Self-Management Support, Cambridge University Hospitals.

3

Appendix C7: Case study 2 - Consent form for HCPs

Improving Utilisation of PR - WP1: Consent Form: Healthcare Professionals Version 1. 10th Jan 2017

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Study IRAS Number: 209597

CONSENT FORM: Healthcare Professionals

Full title of Project: Applying inclusive design to improve people's experience of accessing pulmonary rehabilitation

Name of Researcher: **Yuanyuan Liu**

Please tick the boxes if you agree with the statement(s):

1. I confirm that I have read and understood the information sheet dated 10/01/2017 (version 1) I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand my participation is voluntary and I may withdraw at any time without giving any reason and with NO consequences of any kind. ☐

3. I agree that the interview that I take part can be digitally recorded and used solely for the purpose of this research. ☐

4. I understand that all the personal information will remain confidential and that all efforts will be made to ensure I cannot be identified from this information. ☐

5. I agree to the use of anonymised quotes in publications. ☐

6. I agree to take part in the above study. ☐

7. I will like to receive a summary of the results in October 2017 via email / post (Please delete one) at the address below:

Participant ..... **Signature** ..... **Date** .....

Researcher ..... **Signature** ..... **Date** .....

Contact informaton:
Yuanyuan Liu, Engineering Design Centre, Department of Engineering, University of Cambridge, Trumpington Street, Cambridge, CB2 1PZ
Email: yl528@cam.ac.uk *Tel:* 07922281772

Appendix C8: Case study 2 - Schedule of interviewing patients (Version 1)

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Schedule of Interviewing People with COPD

- **Objective of interview:**

The purpose of this interview is to understand people who have been diagnosed with chronic obstructive pulmonary disease (COPD), and their perceptions and experiences of the COPD care journey. People with COPD will be encouraged to share their experience of COPD treatment.

- **Interview facilitator:**

Yuanyuan Liu: A PhD Candidate in the Engineering Design Centre at the Engineering Department of the University of Cambridge. This project is one part of her PhD project.

- **Opening**

- Introduction:

Good morning/ afternoon. My name is Yuanyuan Liu. I am a PhD student from the University of Cambridge. Thank you very much for agreeing to have an interview.

- Questions for icebreaker:
  - What is your name?
  - How are you today?
  - Did you have a good journey here today?
  - Are you happy to start now?
    If you are not feeling well enough, please feel free to stop me.

- What is the research about?

The aim of this research is to ensure that as many people with COPD as possible enter PR by identifying barriers to access. In particular, those barriers are caused by not taking into account the reduced capabilities (including vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) of people with COPD.

- **Body**

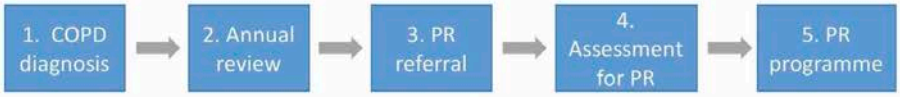
At this point, I am interested in learning from your experience of receiving COPD treatment.

Questions for interview

- **COPD journey of people with COPD:**
  - Who referred you to pulmonary rehabilitation? What happened just before you were referred?
  - How did they you may benefit from pulmonary rehabilitation?

Appendix C8: Case study 2 - Schedule of interviewing patients (Version 1) (continued)

- Looking at the picture, are there any differences in the care journey you may have experienced?



(You may wonder what a care journey is. A care journey refers to a sequence of activities to allow you to receive care. I can give you a similar example, i.e., eating. If you would like to have a dinner in a very popular restaurant, you may need to book in advance. Once you have booked, some factors such as the traffic and location will affect whether you or not arrive on time. During the meal, the service of the waiters, the atmosphere and, of course, the food will all affect your eating experience. After the meal, you will judge the experience in your own way. The booking, the journey to the restaurant and meal all from part of the journey of eating.)

- Can you possibly help me identify your care journey? From your perspective, which part of the care journey do you think is most challenging? And which part would be relatively easier for you?
  Probes: Could you possibly tell me more about your needs along the journey?

- **Needs of people with COPD**
- Have you ever been referred to pulmonary rehabilitation? Can you recall your experience when you had just been referred to pulmonary rehabilitation? Is this your first time to do pulmonary rehabilitation or not? If not, are there any differences between the 1st and 2nd time?
  Probes: What was your feeling at that time? Can you tell me more about------?

- Can you remember the first time you talked with your physiotherapist in the rehab centre? Can you remember what they told you?
  Probes: How you communicate with your physiotherapist/GP/practice nurse/doctor?

- How do you feel about pulmonary rehabilitation? Do you think it is helpful?
  Probes: Could you tell me more about------?

- In your experience of accessing pulmonary rehabilitation, which things do you think do you think good? And what things do you think could be better?
  Probes: What about------ is it that made it so bad? Why do you think ----- is bad?

- Are there things that you think would have improved your pulmonary rehabilitation experience?
  Probes: Could you tell me more about------?

- **The relationship between capabilities and accessibility**
- Here we are going to do a capability measure test. There will be about 6 sets of questions.

2

Appendix C8: Case study 2 - Schedule of interviewing patients (Version 1) (continued)

A measure tool, the Cambridge exclusion calculator, contains questions that will be used to measure people's capability. The website of this tool is http://www.inclusivedesigntoolkit.com/betterdesign2/exclusioncalc/exclusioncalc.html

- How long have you been diagnosed with COPD? Have there been any significant changes in your life since your diagnosis?

- Do you think your capabilities (i.e., how well your vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) will affect your access to pulmonary rehabilitation or not?

- Have there been any changes in your capabilities (vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) since you were diagnosed? Do these changes affect your pulmonary rehabilitation especially the uptake and attendance process?
  Probes: Would you tell me more about------?

Personal information

- Would you mind me asking you some personal information?
  What is your occupation?
  May I know the first 3 letters of your postcode?
  Would you be willing to say when you were born?

- **Closing**

Thank you very much for your time. Your answers are very helpful. Are there any questions you would like to ask me? I may contact you for further information. Thank you so much.

- **Others**

The overall interview time is about 40 mins.
(We aware some people may need some rest during the interview, so the interview duration may be extended.)

3

Appendix C9: Case study 2- Questions for measuring people's capability

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS NHS Foundation Trust

Here we are going to do a capability measure test. There will be about 6 sets of questions.

1. VISION

- Do you use glasses?
- Can you see well enough to read a newspaper headline (with your glasses)?
- Can you see well enough to read a large print book (with your glasses)?
- Can you see well enough to read the ordinary newspaper print (with your glasses)?
- Can you see well enough to read GP's letter or medication instruction (with your glasses)?
- Has your vision affected your access to (get to) COPD care treatment or not?

2. HEARING

- Can you understand loud speech in a quiet room?
- Can you use the telephone without special adaptations for hearing impairment?
- Do you have great difficulty following a conversation if there is background noise – for example, a T.V., radio or children playing?
- Can you see hear your GP or physiotherapists' words clearly?
- Has your hearing affected your access to (get to) COPD care treatment or not?

3. THINKING

- Can you concentrate on a short TV ad without getting distracted?
- Can you concentrate enough to make toast without getting distracted?
- Can you concentrate enough to run a bath without getting distracted?
- Can you think clearly, or do your thoughts tend to be muddled or slow?

THINKING - Memory

- Can you remember your name?
- Can you remember your best friend's name?
- Can you remember names of people in your family or friends whom you see regularly?

THINKING - Literacy

- Can you read and understand individual common words, e.g. cat, house?
- Can you read and understand a sentence, i.e., in a tabloid newspaper?
- Can you read and understand a short newspaper article, i.e., in a tabloid newspaper?

THINKING - Speaking comprehension

- Can you understand individual common words when spoken aloud?
- Can you understand simple sentences when spoken aloud?
- Can you understand short audio news report?

THINKING - speaking

- Can you speak common words clearly enough that others can understand?
- Can you ask a simple question clearly enough that others understand it?
- Can you speak clearly enough that others understand you in typical everyday conversations?
- Do you have any difficulty to answer questions and talk with your GP or physiotherapists?
- Has your thinking and communication affected your access to (get to) COPD care treatment or not?

1

Appendix C9: Case study 2- Questions for measuring people's capability (continued)

4. DEXTERITY

- Can you turn a tap or the control knob of a cooker?
- Can you pick up a small object, like a safety pin from a table-top using your fingers
- Can you use a pen or pencil to write without difficulty?

DEXTERITY - Lifting strength

- Can you pick up and hold a mug of coffee or tea by the handle?
- Can you pick up and carry a bottle of wine or a glass bottle of milk without condensation?
- Can you pick up and carry four pints of milk or a 2.5kg bag of potatoes?
- Has your dexterity affected your access to (get to) COPD care treatment or not?

5. REACH AND STRETCH - reach forward and up

- Can you reach forward to shake hands with your friends?
- Can you reach up to put a hat on head?
- Can you reach something just above head for a few seconds?

REACH AND STRETCH - reach down

- Can you reach down to knee level with one arm, supporting yourself with other arm if needed?
- Can you reach down to the floor level with one arm, supporting yourself with the other arm if needed?
- Can you get down to floor level to use dustpan& brush, supporting yourself on the way if needed?
- Has your reach and stretch affected your access to (get to) COPD care treatment or not?

6. MOBILITY

- What is the furthest you can walk on your own without stopping and without severe discomfort?

☐ I am able to walk only a few steps.
☐ I am able to walk 50m without help and without stopping, with aids if needed.
☐ I am able to walk 175m without help and without stopping, with aids if needed.
☐ I am able to walk 350m without help and without stopping, with aids if needed.
☐ Not sure

- What is the longest stairs you can climb on your own without stopping and without severe discomfort?

☐ I am able to climb 12 stairs without help and without using a handrail.
☐ I am able to climb 12 stairs without help, using a handrail if necessary.
☐ I am able to climb one step without help.
☐ I always require assistance.
☐ Not sure.

- Which one is more match your Standing and balancing ability?

☐ I am able to stand momentarily, without holding on to anything
☐ I am able to stand for a minute, without holding on to anything.
☐ I am able to stand for 10 minutes, without holding on to anything
☐ Not sure.

Has your mobility affected your access to (get to) COPD care treatment or not?

2

Appendix C10: Case study 2- Schedule of interviewing patients

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Schedule of Interviewing people with COPD

- **Introduction:**

Good morning/ afternoon. My name is Yuanyuan Liu. I am a PhD student from the University of Cambridge. Thank you very much for agreeing to have an interview.

Questions for icebreaker:

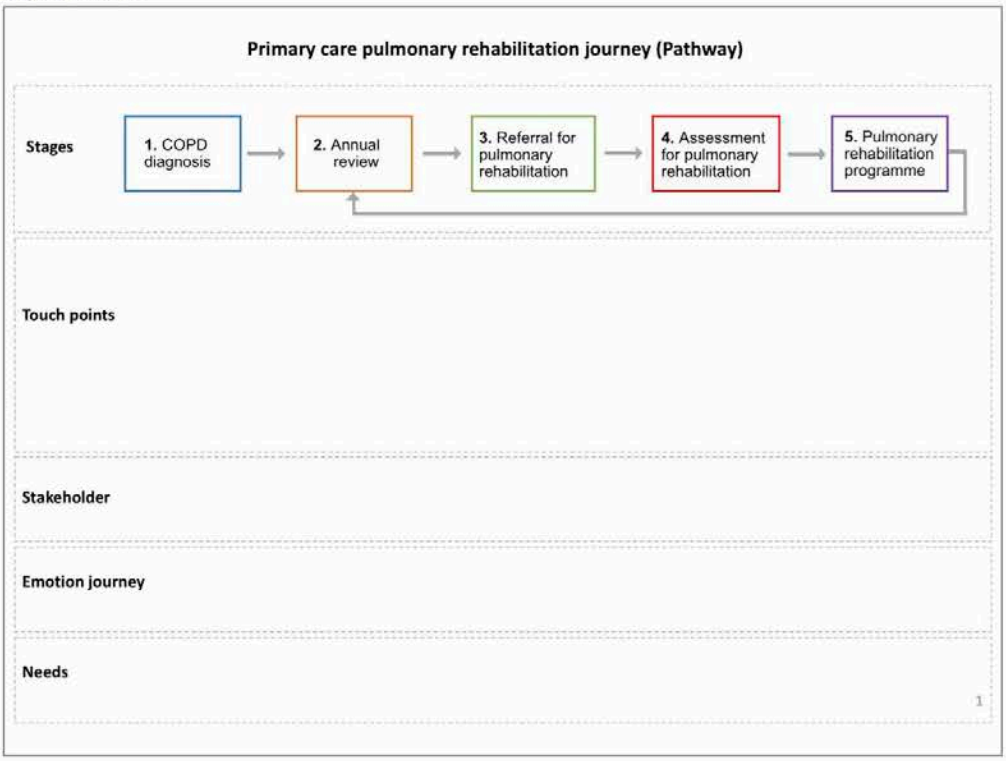
- What is your name?
- How are you today?
- Did you have a good journey here today?
- Are you happy to start now?

  If you are not feeling well enough, please feel free to stop me.

- **COPD journey of people with COPD:**
- Have you ever heard care journey?

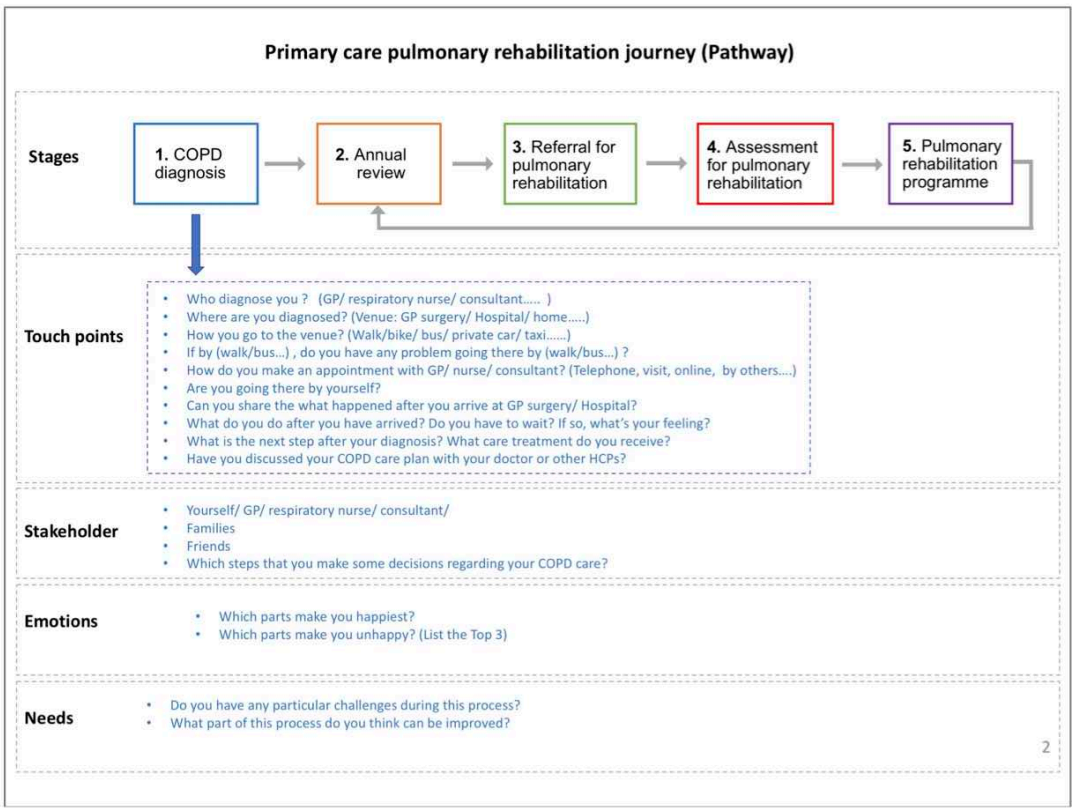
  A care pathway/journey refers to the process that people go through in order to receive/ deliver care. I can give you a similar example, i.e., eating. If you would like to have a dinner in a very popular restaurant, you will go through the booking, the journey goes to the restaurant eating and go back. The whole process we call it journey, so some people prefer to say patient's journey, but some people prefer care pathway from medical perspective.

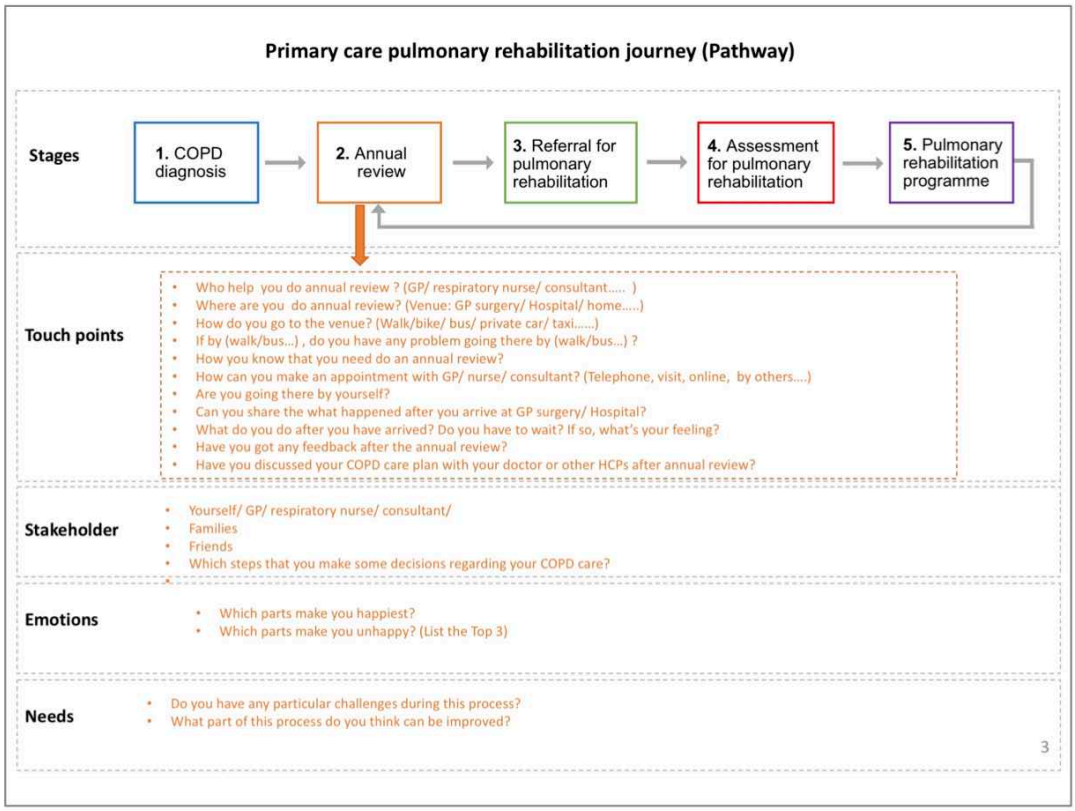
- Looking at the picture, are there any differences in the care journey you may have experienced?



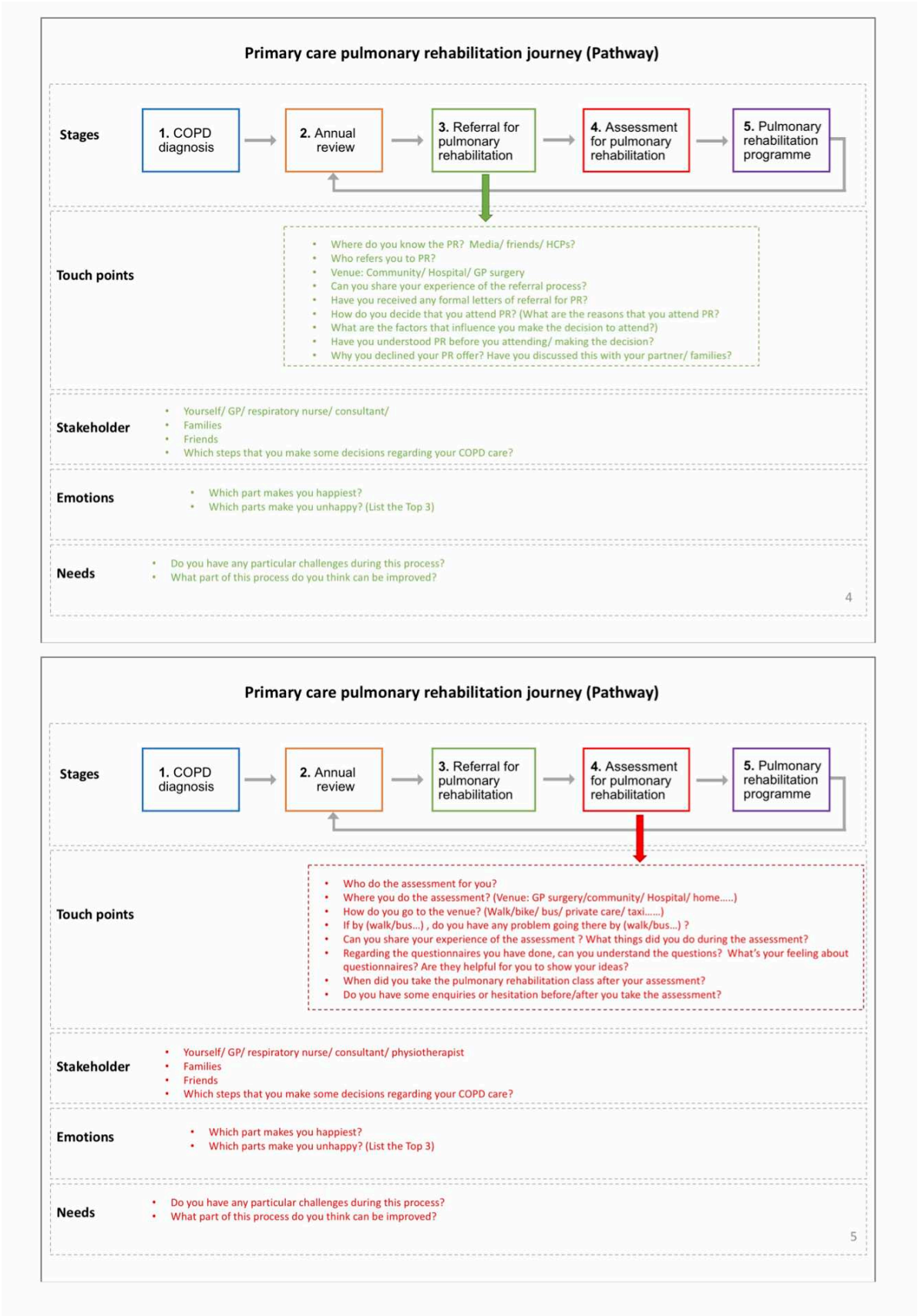
Appendix C10: Case study 2 - Schedule of interviewing patients (continued)

Then the following 5 cards are used to guide the interview.

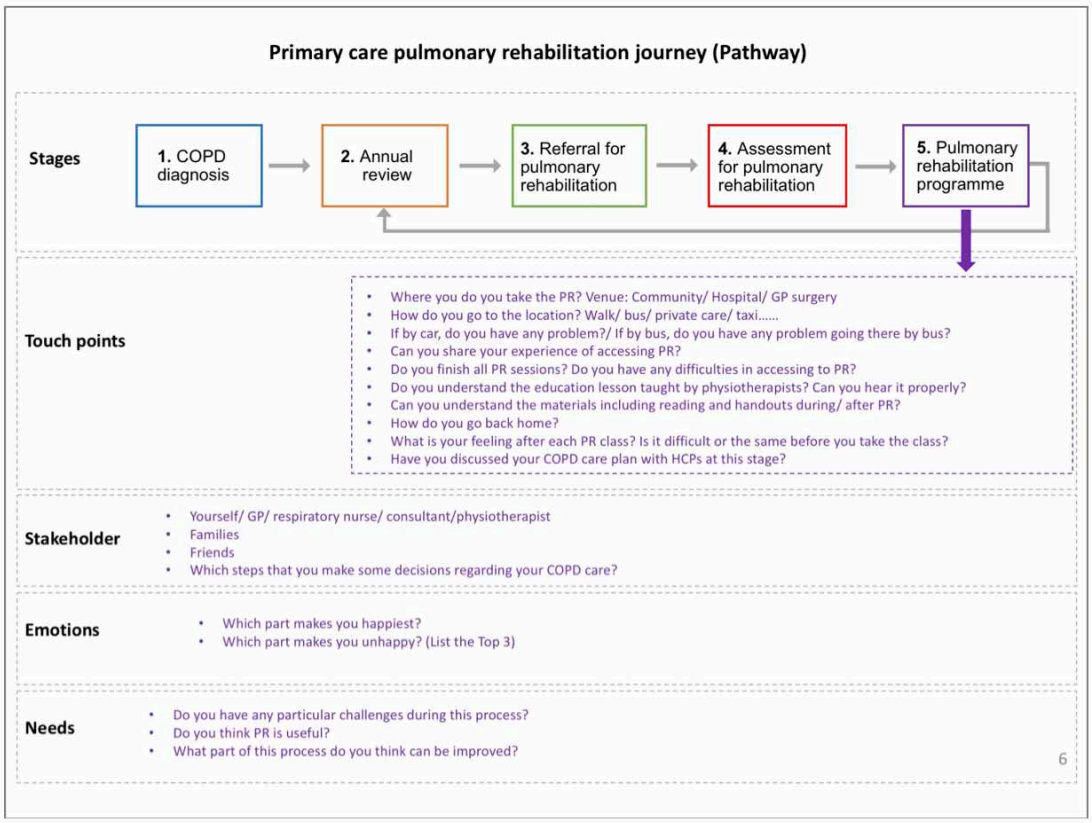




Appendix C10: Case study 2 - Schedule of interviewing patients (continued)

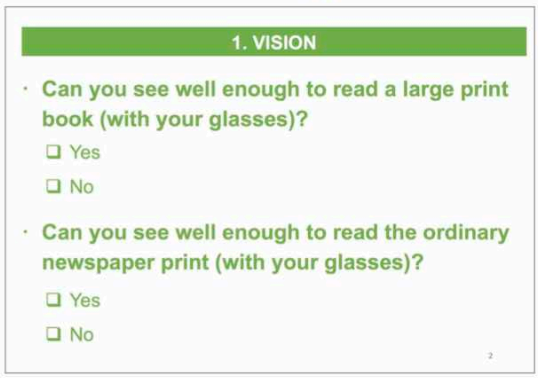


Appendix C10: Case study 2 - Schedule of interviewing patients (continued)



- **Assess people's capabilities**

Here we are going to do a capability measure test. There will be about 6 sets of questions. (The questions are printed on A5 size paper, and detailed questions see appendix 12.)



- **Personal information**

· Would you mind me asking you some personal information?
· What is your occupation?
· May I know the first 3 letters of your postcode?
· Would you be willing to say when you were born?
·

- **Closing**

Thank you very much for your time. Your answers are very helpful. Are there any questions you would like to ask me? I may contact you for further information. Thank you so much.

Appendix C11:
Case study 2 - Invitation letter for interviewing Patient who has accepted PR referral

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Header and logo of PR provider

From: PR providers
To: Patient who has accepted PR referral

Dear *<patient who has accepted PR referral>*

Project title:

Improving people's experience of accessing pulmonary rehabilitation

I am writing to invite you to take part in an interview as part of a research study undertaken by Yuanyuan to help increase the number of people with COPD who are able to attend pulmonary rehabilitation. As you may know, pulmonary rehabilitation is a programme of supervised exercise and education that is recommended by the National Institute for Health and Care Excellence (NICE) for people who are troubled by breathlessness. It helps to improve symptoms, improve quality of life and reduce the number of times that patients need to be admitted to hospital.

I have enclosed an information sheet (version n) that gives you a taste of the study, which I hope will encourage you to participate in the study. The interview can be arranged at a time and a location that are convenient for you. The interview content is mainly about your experience of receiving COPD treatment, for example which things they find easy or difficult in order to access the pulmonary rehabilitation service.

I will contact you within the next few days to explain a little more about the study and answer any questions you may have. If, however, you would like to contact the PhD student, Yuanyuan (details on the attached sheet) directly please don't hesitate to call – we will happily phone you back to save your telephone costs.

Yours sincerely
Contact details

1

Appendix C12:
Case study 2 - Invitation letter for interviewing Patient who has never been referred

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Dear *<patient who has never been referred>*

Can you help us improve how we refer people to pulmonary rehabilitation?

I am writing to invite you to take part in an interview as part of a research study undertaken by Daisy to help increase the number of people with COPD who are able to attend pulmonary rehabilitation. From your records I see that you have not been referred to pulmonary rehabilitation. We would like to talk to people like you who have not been referred to hear about your experience of COPD care and any discussions you may have had with your nurse or doctor about PR. This would be of great help to the study.

We can arrange the interview at a time and location that is convenient for you or by phone if you prefer.

As you may know, pulmonary rehabilitation is a programme of supervised exercise and education that is recommended for people who are troubled by breathlessness from lung disease. We know from evidence that it helps to improve symptoms and quality of life and reduces the number of times that patients need to be admitted to hospital. However, not everyone who can benefit is referred and some patients do not wish to take up the offer. We want to find out how we can help more people get the benefits of pulmonary rehabilitation.

I have enclosed an information sheet and a brief research introduction to give you a taste of the study and I hope it will encourage you to take part. If you would like to know more, please contact researcher, Daisy (details on the attached sheet).

If you would like to take part, please return the slip below to your nurse. We will then contact you with further details.

Thank you very much.

Yours sincerely

xxx Surgery/ Practice

.....

Improving people's experience of accessing pulmonary rehabilitation

I would like to take part in the interview on <date> at <place>. (Please fill in the blank)

Name

Address

Phone Email

Appendix C13: Case study 2 - Invitation letter for interviewing Patient who has declined PR

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS NHS Foundation Trust

Dear *<patient who has declined PR>*

Can you help us improve people's experience of accessing pulmonary rehabilitation (PR)?

I am writing to invite you to take part in an interview as part of a research study undertaken by Daisy to help increase the number of people with COPD who are able to attend pulmonary rehabilitation. I understand that you have had a referral to PR in the past and so it would help us to know about your experience of the referral process.

We can arrange the interview at a time and location that is convenient for you or by phone if you prefer.

We know from evidence that PR helps to improve symptoms and quality of life and reduces the number of times that patients need to be admitted to hospital. However, not everyone who can benefit is referred and some patients do not wish to take up the offer. We want to find out how we can help more people access the benefits of PR.

I have enclosed an information sheet and a brief research introduction to give you a taste of the study and I hope it will encourage you to take part. If you would like to know more, please contact me or the researcher, Daisy (details on the attached sheet). We will happily phone you back to save your telephone costs.

If you would like to take part, please return the slip below in the enclosed stamped addressed envelope. We will then contact you with further details.

Thank you very much.

Yours sincerely

Healthcare professional known to the patient

.....

Improving people's experience of accessing pulmonary rehabilitation

I would like to take part in the interview on <date> at <place>. (Please fill in the blank)

Name

Address

Phone Email

Appendix C14: Case study 2 - Participant Information Sheet for interviewing patients

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Interview Participant Information Sheet for People with COPD

IRAS Number: 209597

Short title: Improving utilisation of pulmonary rehabilitation-WP1

Full research title: Applying inclusive design to improve people's experience of accessing pulmonary rehabilitation (PR) within the community

We would like to invite you to participate in the *improving utilisation of pulmonary rehabilitation* research project. It is important that you understand what this research is about and what it will involve. This will help you decide whether or not to take part. Please take your time to read the following information carefully. If you have any questions about this study, please contact us using the contact details below. Your participation is **entirely voluntary**.

1. What is the purpose of this research study?

Approximately 1.2 million people in the UK have Chronic Obstructive Pulmonary Disease (COPD) causing breathlessness, difficulty with daily activities, frequent infections and hospitalisation. Pulmonary rehabilitation (PR), provides supervised exercise and advice to help control symptoms, improves quality of life and avoids hospitals admissions. Some people with COPD do not receive PR because either healthcare professionals do not refer them or they do not know about it. Of those referred 31% do not take up the offer. There are no well-proven solutions that increase the number of people attending PR.

There are two ways to increase the number of people with COPD who may benefit from PR: one is to improve the referral rate for PR, the other is to increase people's opportunity to take up the programme. My research is focused on both. It will look at the whole COPD care journey including the process of diagnosis, annual review, referral to PR, assessment for PR, access to and after finishing PR to ensure the maximum number of people access to PR. Specifically, it will focus on identifying barriers that affect the referral and uptake process. In particular, those barriers are caused by not taking into account the reduced capabilities (including vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) of people with COPD. This will inform ways to increase the number of people accessing PR.

In order to achieve this aim, it is important to first understand the requirements and expectations that people may have when they access the PR.

2. Who can take part this research study?

You can take part if:

- You have been diagnosed with COPD
- You are happy to share your experience about accessing treatment of COPD.
- You are able to speak and understand the English language.

Appendix C14:

Case study 2 - Participant Information Sheet for interviewing patients (continued)

3. Why are we asking for your help?

We need your help with this work because you have had experience of COPD care. Your first-hand feedback is of utmost importance to us.

4. Do you have to take part?

NO. It is up to you to decide whether or not to take part. If you agree to participate, you will be given this information sheet to keep and be asked to sign a consent form.

5. How can you take part?

An interview will take place on community premises where pulmonary rehabilitation classes are conducted, or where Breathe Easy support groups' meetings are held or a choice of location of either the Engineering Department of University of Cambridge or your home with someone accompanying the researcher. It will take approximately 50 minutes.

We will focus on your experiences and understanding of how services are delivered. If you give permission, interviews will be audio recorded. Alternatively, the researcher will take notes. Data will be transcribed and stored anonymously and securely.

With your permission we will inform your GP of your involvement in the project.

6. Can you withdraw from the project at any stage?

YES. If you decide not to take part after you have signed a consent form, this will not affect you in any way and there will be no consequences for your care. If you withdraw from the project at any stage, you do not need to give a reason and any of the information you have already contributed until that point will remain part of the project.

7. Will my taking part in this project be kept confidential?

YES. All data collected in this study will be kept confidential and cannot be traced back to you. No participant will be identified by name or organisation in any publication. Direct quotations will be used in PhD thesis and publications but these will be completely anonymised and cannot be identified with any individual. The data collected will only be accessible to the research team. The audio recording of the interviews will be stored on a secure computer, in a restricted-access server at the Engineering Department of the University of Cambridge. Only the research group has access to this information and the protocols for protecting confidentiality are very strict. On completion of the study, all information held will be stored in a secure place and destroyed after 5 years.

8. What will happen to the information you provide?

Information collected from participants in this project will help to understand people's perceptions and experiences of pulmonary rehabilitation. The data will also help to understand people's needs when they access pulmonary rehabilitation.

9. What are the possible benefits of taking part?

Your contribution will be valuable. The findings will provide researchers with a better understanding of people's perception and experience of COPD care. This in turn will help care providers further understand the needs of people with COPD and provide an improved PR experience to them. The participants will be remunerated for transport. Research findings will be shared if requested.

2

Appendix C14:

Case study 2 - Participant Information Sheet for interviewing patients (continued)

10. What are the possible disadvantages and risks of taking part?
There are no disadvantages or risks in taking part in this interview. You can stop and have some rest when you feel tired or uncomfortable during the interview. If you have carers (e.g. a carer, family member, friend), they are more than welcome to accompany with you.

11. How will the findings be used?
The findings of this study will be will be presented in the researcher's PhD thesis. It may also be presented at conferences and written up in journals. It will help care providers better understand the needs of people with COPD. The results will also be fed into a project focused on improvement of referral and uptake of PR. This will ultimately improve people's PR experience. A lay summary of findings will be sent to you if you wish.

12. How has this study been funded?
This research is a PhD research project, and the researcher is funded by the China Scholarships Council (CSC). The funding provided by CSC covers the researcher's tuition and living expenses in the University of Cambridge.

13. What if there is a problem or I want to make a complaint?
If you have a concern or complaint about the research study and wish to speak to somebody who is independent of the study, you can do this by contacting the Patient Advice and Liaison Service (PALS) of Cambridge University Hospital (CUH) at:
Box 53, Cambridge University Hospitals, Cambridge Biomedical Campus, Hills Road, Cambridge, CB2 0QQ.
Phone: 01223 216 756 (Monday to Friday: 09:00—16:00); Email: pals@addenbrookes.nhs.uk

14. What happens now?
If you decide to take part in this research project, please let us know by sending an email to yl528@cam.ac.uk or calling to 01223 748 577 or texting to 07922 281 772. Please let us have details of your address, phone or email address to enable us to discuss when and where the interview will take place. If you decide not to continue taking part at any point, just let us know and you do not need to do anything more. We will remove your contact details from the project.

Further information
Thank you very much for your time. Please keep this information sheet in a safe place. If you need more information, please text or call at the dedicated research mobile: 07922 281 772

Research Team:
Researcher: Yuanyuan Liu, PhD candidate, Department of Engineering, University of Cambridge.
Supervisors: Professor P John Clarkson, Director of EDC, University of Cambridge;
Dr. Terry Dickerson, Senior Research Associate, University of Cambridge.
Collaborators: Jonathan Fuld, Consultant Physician, Cambridge University Hospitals;
Frances Early, Centre for Self-Management Support, Cambridge University Hospitals.

3

Appendix C15: Consent form for people with COPD

Improving Utilisation of PR - WP1: Consent Form: People with COPD Version 1. 10th Jan 2017

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Study IRAS Number: 209597

CONSENT FORM: People with COPD

Full title of Project: Applying inclusive design to improve people's experience of accessing pulmonary rehabilitation

Name of Researcher: **Yuanyuan Liu**

Please tick the boxes if you agree with the statement(s):

1. I confirm that I have read and understood the information sheet dated 10/01/2017 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that I am free to invite a friend or family member to accompany me during the interview if it makes me feel more comfortable. ☐
4. I agree that the interview that I take part can be digitally recorded and used solely for the purpose of this research. ☐
5. I understand that all the personal information will remain confidential and that all efforts will be made to ensure I cannot be identified from this information. ☐
6. I agree to the use of anonymised quotes in publications. ☐
7. I agree to my GP being informed of my participation in the above study. ☐
8. I agree to take part in the above study. ☐
9. I will like to receive a summary of the results in Oct 2017 via email / post (Please delete one) at the address below: ☐

Participant ..... **Signature** ..... **Date** .....

Researcher ..... **Signature** ..... **Date** .....

Contact information:
Yuanyuan Liu, Engineering Design Centre, Department of Engineering, University of Cambridge, Trumpington Street, Cambridge, CB2 1PZ
Email: yl528@cam.ac.uk *Tel:* 07922281772

Appendix C16: A list of codes and their definitions for analysing interview data

Category	Code	Definition (Generic)	Interpretation (In relation to PR)
Stage	COPD Diagnosis	The diagnosis is suspected on the basis of symptoms (particularly breathlessness or cough) and signs and supported by spirometry.	any activities happened or relate to this stage comments/ suggestions regarding improve diagnosis
	Annual Review	All patients with COPD are required to have an annual/ six-monthly review to check their symptom control, inhaler technique, lung function, oxygen saturation if required, have a general medication and physical health check, offer help if smoking and review an individual care plan for what to do if become unwell.	any activities happened or relate to this stage comments/ suggestions regarding improve annual review
	PR referral	Patients with COPD who are eligible to PR are referred by HCPs	any activities happened or relate to this stage comments/ suggestions regarding improve PR referral
	Assessment for PR	This section has been developed to help with the assessment of patients referred for pulmonary rehabilitation	any activities happened or relate to this stage comments/ suggestions regarding improve assessment
	Pulmonary Rehabilitation (PR)	Pulmonary rehabilitation is a programme of exercise and education for people with a long-term lung condition (BLF).	any activities happened or relate to this stage comments/ suggestions regarding improve PR
	after PR	The stage that patients have finished PR programme	any activities happened or relate to this stage comments/ suggestions that can help self-manage COPD
Profile	Patients' profile	A description of patients that gives useful information	Patients basic information such as age and job, and COPD related information, e.g., the length of diagnosis.
	HCPs' profile	As defined in the UK, a healthcare professional is a person associated with either a specialty or a discipline and who is qualified and allowed by regulatory bodies to provide a healthcare service to a patient. (Medical dictionary)	all the healthcare professionals that patients who suitable for PR may need to contact; it also including HCP's role and their organisations
Patients' activities/ tasks of their care journey	Make an appointment	A formal arrangement to meet or visit somebody at a particular time, especially for a reason connected with their work	A formal arrangement to meet HCPs
	Transport	A system for carrying people or goods from one place to another using vehicles, roads, etc. A vehicle or method of travel	Access or lack of access to convenient, affordable means of attending appointments and/or PR.
	Consult HCPs	To go to HCPs for information or advice	Visit HCPs (GPs, nurses, physiotherapists) for their COPD conditions
	Checked by HCPs	check something (for something) to examine something to see if it is correct, safe or acceptable by HCPs (ref. OD)	examined by HCPs such as chest to see whether have COPD
	Receive treatment	treatment (for something) something that is done to cure an illness or injury, or to make somebody look and feel good	Receive something to control/manage COPD conditions
	make decisions	the process of deciding about something important (ref. OD)	A choice of action chosen by a patient, including all the decisions that patients make when they access PR.
	request help	the action of asking for help formally and politely. (ref. OD)	the action of asking for help about COPD
Patients' experience along care journey	Patients' emotions	a strong feeling such as love, fear or anger; the part of a person's character that consists of feelings. (ref. OD)	refers to how a patient's emotions are affected by PR.
	Patients' challenges (capability related)	challenge refers to a new or difficult task that tests patients' ability and skill; an invitation or a suggestion to patients that they should enter a competition, fight, etc. (ref. OD)	Any capability (vision, hearing, thinking, reach and dexterity, and mobility) related difficulties that a patient may have to overcome in order for them to engage in PR.
	Patients' challenges (Non-capability related)	challenge refers to a new or difficult task that tests patients' ability and skill; an invitation or a suggestion to patients that they should enter a competition, fight, etc. (ref. OD)	Any non-capability related difficulties that a patient may have to overcome in order for them to engage in PR.
HCPs' activities/ tasks of their care pathway	Have an appointment	A formal meet with patients at a particular time (ref. OD)	A formal meet with patients who may have COPD at a particular time
	Undertake consultation	Provide information or advice to patients (ref. OD)	Provide information or advice to patients who may have COPD
	Refer patients	the act of sending patients who needs professional help to a person or place that can provide it (ref. OD)	the act of sending patients who needs professional help to a person or place that can provide it
	Check patients' health	check something (for something) to examine something to see if it is correct, safe or acceptable for patients (ref. OD)	examine patients' such as chest to see if patients have COPD by HCPs (ref. OD)
	Educate patients	To teach patients about something or how to do something	to teach patients about COPD and how to do control it
	Offer treatment	Provide something that is done to cure an illness or injury, or to make somebody look and feel good (ref. OD))	Provide something that is done to cure/control an illness or injury, or to make patients look and feel good
	Discuss care plan	Discuss with patients how to take care of their conditions	Discuss with patients how to take care of their COPD conditions
	Make clinical decision	the process of deciding about some important clinical choice. (ref. OD)	A choice of action chosen by or recommended by a health care professional.
	Sell PR	To persuade somebody that PR is a good idea, service, product, etc. (ref. OD)	to persuade patients that PR is a good idea, service, product, etc.
	Do assessment	the act of judging or forming an opinion about patients (ref. OD)	the act of judging or forming an opinion about patients' condition
	Inform patients	To tell patients about something, especially in an official way (ref. OD)	To tell patients about the diagnosis of COPD in an official way

Appendix C16: A list of codes and their definitions for analysing interview data (continued)

HCPs' experience along care pathway	HCPs' emotion	A strong feeling such as love, fear or anger; the part of a person's character that consists of feelings. (ref. OD)	HCP's feelings during the process they meet/consult a COPD patient
	HCPs' challenges	Challenge refers to a new or difficult task that tests HCPs' ability and skill; an invitation or a suggestion to HCPs that they should enter a competition, fight, etc. (ref. OD)	Any difficulties that HCPs may have to overcome in order to promote PR.
Care related	HCPS' perceptions about PR	perception refers to an idea, a belief or an image HCP have as a result of how they see or understand something. (ref. OD)	Healthcare professionals' views about pulmonary rehabilitation (PR)
	Patients' perceptions about PR	perception refers to an idea, a belief or an image patient have as a result of how they see or understand something. (ref. OD)	Patients' views about pulmonary rehabilitation (PR)
	Patients' knowledge about COPD care	No applicable	Patients' knowledge about COPD care specially about PR services.
	HCP's knowledge about COPD care	No applicable	HCPs' knowledge about COPD care specially about PR services.
	Patients' education	Education: a particular kind of teaching or training	Teaching or training to patients about care, especially for COPD (PR)
	HCP & patients' relationship	the way in which two people, groups or countries behave towards each other or deal with each other. (ref. OD)	patients/HCPs' views about their relationships between each other, including the relationships' impacts
	Communication between HCPs	the activity or process of expressing ideas and feelings or of giving people information. (ref. OD)	all the communication between different HCPs that relate to COPD care
	Communication between HCPs and patients	the activity or process of expressing ideas and feelings or of giving people information. (ref. OD)	all the communication between HCPs and patients that relate to COPD care
	Factors affect uptake and attendance	No applicable	HCP and patients' experiences or perceptions about the factors that would affect patients' uptake and attend PR
Recommendation	Patient's expectation	a hope that something good will happen (ref. OD)	Relates for aspirations that a patient has in relation to PR.
	Patients' needs (from HCP)	needs refer to requirements of patients because they are essential or very important, not just because you would like to have them. (ref. OD)	healthcare professionals' views regarding the needs that patients need in order to enable them to access PR
Support Networks	Apps	Application software (app or application for short) is a computer software designed to perform a group of coordinated functions, tasks, or activities for the benefit of the user. (wiki)	A Software 'Application' that can be used to help an individual access any part of the process for accessing PR. This includes diagnosis, treatment, monitoring, aftercare and selfcare.
	Personal support network	No applicable	An individual or group (not HCPs or organisational) of people that can give physical, psychological and/or social support to a person undergoing medical treatment.
	Organisation support network	No applicable	One or more professional organisations that can give physical, psychological and/or social support to a person undergoing medical treatment.
	Information channel	No applicable	refer to channels that patients can obtain information regarding PR Treatment.
Others	Motivation	refers the feeling of wanting to do something, especially something that involves hard work and effort. (ref. online Oxford Dictionary=OD)	refer to patients' feeling of wanting to improve their health, activity levels and symptom reduction by engaging with PR.
	Sociability	refers to whether the patient enjoy spending time with other people (ref. OD)	refers to a patient pending time with other people during activities including group-based PR.
	Confidence	a belief in your own ability to do things and be successful (ref. OD)	refers to patients' feeling of self-assurance regarding PR that arises from an appreciation of their own abilities or qualities.

Note: this research only identifies the COPD care pathway (journey) that related to patients' access PR services. Patients' ability to do exercises and take part in PR once they have accessed the service, and the PR programme were not the focus of this research.
The research questions are below:

- What are the care journeys of people with COPD?
- To what extent do people's capabilities affect their access to community-based PR services?
- How can we use the principle of Inclusive Design to address barriers along the PR journey?
- Is Inclusive Design useful to improve the healthcare experience of people with COPD in the community?

References:

Patients' information: https://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/overview.aspx
Self-care: https://www.england.nhs.uk/blog/what-does-self-care-mean-and-how-can-it-help/
Mental health: http://www.who.int/whr/2001/chapter1/en/index1.html
OD: oxford dictionary (online version)

Appendix C17: Case study 2 - Participant Information Sheet for focus group

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Focus Group Participant Information Sheet for People with COPD

IRAS Number: 209597

Short title: Improving utilisation of pulmonary rehabilitation-WP1

Full research title: Applying inclusive design to improve people's experience of accessing pulmonary rehabilitation (PR) within the community

We would like to invite you to participate in the *improving utilisation of pulmonary rehabilitation* research project. It is important that you understand what this research is about and what it will involve. This will help you decide whether or not to take part. Please take your time to read the following information carefully. If you have any questions about this study, please contact us using the contact details below. Your participation is **entirely voluntary**.

1. What is the purpose of this research study?

Approximately 1.2 million people in the UK have Chronic Obstructive Pulmonary Disease (COPD) causing breathlessness, difficulty with daily activities, frequent infections and hospitalisation. Pulmonary rehabilitation (PR), provides supervised exercise and advice to help control symptoms, improves quality of life and avoids hospitals admissions. Some people with COPD do not receive PR because either healthcare professionals do not refer them or they do not know about it. Of those referred 31% do not take up the offer. There are no well-proven solutions that increase the number of people attending PR.

There are two ways to increase the number of people with COPD who may benefit from PR: one is to improve the referral rate for PR, the other is to increase people's opportunity to take up the programme. My research is focused on both. It will look at the whole COPD care journey including the process of diagnosis, annual review, referral to PR, assessment for PR, access to and after finishing PR to ensure the maximum number of people access to PR. Specifically, it will focus on identifying barriers that affect the referral and uptake process. In particular, those barriers are caused by not taking into account the reduced capabilities (including vision, hearing, mobility, reach and stretch, dexterity, thinking and communication) of people with COPD. This will inform ways to increase the number of people accessing PR.

In order to achieve this aim, it is important to first understand the requirements and expectations that people may have when they access the PR.

2. Who can take part this research study?

You can take part if:

- You have been diagnosed with COPD
- You are happy to share your experience about accessing treatment of COPD.
- You are able to speak and understand the English language.

Appendix C17: Case study 2 - Participant Information Sheet for focus group (continued)

3. Why are we asking for your help?
We need your help with this work because you have had experience of COPD care. Your first-hand feedback is of utmost importance to us.

4. Do you have to take part?
NO. It is up to you to decide whether or not to take part. If you agree to participate, you will be given this information sheet to keep and be asked to sign a consent form. With your permission we will inform your GP of your involvement in the project.

5. How can you take part?
A focus group will take place during the Breathe Easy support groups' meeting. The purpose of this focus group is to check the feasibility of a framework / approach that aims to help healthcare professionals better understand patients' needs. We are interested in listening to your comments and suggestions about the framework / approach.
It will take approximately 40 minutes. If you give permission, the focus group will be audio recorded. Alternatively, the researcher will take notes. Data will be transcribed and stored anonymously and securely.
With your permission we will inform your GP of your involvement in the project.

6. Can you withdraw from the project at any stage?
YES. If you decide not to take part after you have signed a consent form, this will not affect you in any way and there will be no consequences for your care. If you withdraw from the project at any stage, you do not need to give a reason and any of the information you have already contributed until that point will remain part of the project.

7. Will my taking part in this project be kept confidential?
YES. All data collected in this study will be kept confidential and cannot be traced back to you. No participant will be identified by name or organisation in any publication. Direct quotations will be used in PhD thesis and publications but these will be completely anonymised and cannot be identified with any individual. The data collected will only be accessible to the research team. The audio recording of the focus group will be stored on a secure computer, in a restricted-access server at the Engineering Department of the University of Cambridge. Only the research group has access to this information and the protocols for protecting confidentiality are very strict. On completion of the study, all information held will be stored in a secure place and destroyed after 5 years.

8. What will happen to the information you provide?
Information collected from participants in this project will help to understand people's perceptions and experiences of pulmonary rehabilitation. The data will also help to understand people's needs when they access pulmonary rehabilitation.

9. What are the possible benefits of taking part?
Your contribution will be valuable. The findings will provide researchers with a better understanding of people's perception and experience of COPD care. This in turn will help care providers further understand the needs of people with COPD and provide an improved PR experience to them. The participants will be remunerated for transport. Research findings will be shared if requested.

2

Appendix C17: Case study 2 - Participant Information Sheet for focus group (continued)

10. What are the possible disadvantages and risks of taking part?
We have not identified any disadvantages or risks in taking part in this focus group. You can stop and have some rest when you feel tired or uncomfortable during the process. If you have carers (e.g. a carer, family member, friend), they are more than welcome to accompany with you.

11. How will the findings be used?
The findings of this study will be will be presented in the researcher's PhD thesis. It may also be presented at conferences and written up in journals. It will help care providers better understand the needs of people with COPD. The results will also be fed into a project focused on improvement of referral and uptake of PR. This will ultimately improve people's PR experience. A lay summary of findings will be sent to you if you wish.

12. How has this study been funded?
This research is a PhD research project, and the researcher is funded by the China Scholarships Council (CSC). The funding provided by CSC covers the researcher's tuition and living expenses in the University of Cambridge.

13. What if there is a problem or I want to make a complaint?
If you have a concern or complaint about the research study and wish to speak to somebody who is independent of the study, you can do this by contacting the Patient Advice and Liaison Service (PALS) of Cambridge University Hospital (CUH) at:
Box 53, Cambridge University Hospitals, Cambridge Biomedical Campus, Hills Road, Cambridge, CB2 0QQ.
Phone: 01223 216 756 (Monday to Friday: 09:00—16:00); Email: pals@addenbrookes.nhs.uk

14. What happens now?
If you decide to take part in this research project, please let us know by sending an email to yl528@cam.ac.uk or calling to 01223 748 577 or texting to 07922 281 772. If you decide not to continue taking part at any point, just let us know and you do not need to do anything more. We will remove your contact details from the project.

Further information
Thank you very much for your time. Please keep this information sheet in a safe place. If you need more information, please text or call at the dedicated research mobile: 07922 281 772 or email to yl528@cam.ac.uk

Research Team:
Researcher: Yuanyuan Liu, PhD candidate, Department of Engineering, University of Cambridge.
Supervisors: Professor P John Clarkson, Director of EDC, University of Cambridge;
Dr. Terry Dickerson, Senior Research Associate, University of Cambridge.
Collaborators: Jonathan Fuld, Consultant Physician, Cambridge University Hospitals;
Frances Early, Centre for Self-Management Support, Cambridge University Hospitals.

3

Appendix C18: Case study 2 - Focus group with patients

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS Foundation Trust

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Schedule of focus group with patients

- **Introduction:**

Greeting: Good Afternoon, everyone. I'm Daisy. As you may know, I am a PhD student from the University of Cambridge, trying to improve people's COPD care experience.
Thank you very much for supporting me in this discussion, which I hope will be a relaxed, interactive and enjoyable experience.

Consent: Before we are starting the discussion, I wonder everyone has read the participant information sheet and consent form? Please sign the consent form if you agree with the content.

Map: I suppose everyone has got the map we just send out? Please let me know if you have
not got a copy.

- Ground rules:
- All views are valuable. There's no right or wrong answer to the questions I will ask. I would like to hear what each of you think about the map.
- All your views should be able to be expressed without fear of being criticised. Therefore, please respect the views of all other people.
- I would like to hear everyone's views and ideas, so I might give people who have not spoken up the opportunity to comment at some point, but do not feel that you must do so.
- Information from this focus group will only be used by the research team and only for research purposes and will be completely anonymised.

- **Body:**

I have developed this the map based on interview with healthcare professionals and people living with COPD. It aims to help you know how you can engage in your COPD care especially the pulmonary rehabilitation and give care providers different perspectives to understand your care needs. At this point, I am interested in listening to your comments and suggestions about it.

Guide questions for interview :

- Do you understand this map? Is there any difference the journey you have experienced? Any comments this process? Please let me know.

- Are thing any parts you think also very important in the COPD diagnosis process/ referral process/ assessment/ PR programme/ annual review?

1

Appendix C18: Case study 2 - Focus group with patients (continued)

- What do you think of the part of the map? Are there any parts that should be included in the map or not?
  Probes: Can you tell me more about------?

Process of the map:

- What do you think about the way of mapping the people's care journey within this map?

Probes: Is the way of mapping the people's care journey described adequately within this map? How could this be improved?

Benefit of the map:

- What do you think about the benefit of the map?

- To People with COPD: Do you think the map could help you better understand the care journey you may go through in order to receive COPD treatment?

- To physiotherapist: Do you think it would help you to gain a better understanding about COPD patients' capability needs?

- *Are there any questions you would like to ask me? Please feel free to ask.*

- **Closure**

Thank you very much for coming this afternoon. Your time is very much appreciated, and your comments have been very helpful. You are very welcome to contact me, if you have any further questions or suggestions. Thank you so much.

2

Appendix C19: Case study 2 - survey with HCPs

UNIVERSITY OF CAMBRIDGE Engineering Design Centre

Cambridge University Hospitals NHS NHS Foundation Trust

Research Project: Improving Utilisation of Pulmonary Rehabilitation

Improving people's experience of accessing pulmonary rehabilitation – what is your professional perspective?

This survey aims to gather your views about the "Your COPD Care Reminder" which aims to help patients manage their COPD care and help you better understand their needs.

This project has been approved by Cambridge Central Research Ethics Committee (17/EE/0136).

The survey will take less than **10 minutes** to complete. Please read the Reminder first and then fill the survey. Thank you very much for your time.

Q1. Is the reminder easy to understand?

- ☐ I understand all of it
- ☐ I understand most of it
- ☐ I understand some of it
- ☐ Not at all
- ☐

Q2. Is it useful to use the patient's care journey to remind them how to manage their care?

- ☐ Very good.
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor

Q3. Is the patient's journey in the reminder good description of the actual journey?

- ☐ Very good.
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor

Q4. What do you think of the elements (diagnosis, information, treatment……) within this COPD care reminder?

- ☐ Very good.
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor

Q5. Are there any other elements that should be included in the reminder?

- ☐ No.
- ☐ Yes. Please add your comments below.

1

Appendix C19: Case study 2 - survey with HCPs (continued)

Q6. Do you think it would help you to gain a better understanding about COPD patients' capability needs or not?

- ☐ Excellent
- ☐ Good
- ☐ Satisfactory
- ☐ Poor
- ☐ Very Poor

Q7. Do you think it would help patients to manage their care better or not?

- ☐ Excellent
- ☐ Good
- ☐ Satisfactory
- ☐ Poor
- ☐ Very Poor

Q8. Have you got any suggestions to improve this reminder? Please feel free to leave any comments above.

Q9. Are you willing to participate a further interview? It will last about 20-30mins, and can be face-to-face at a location of your choice, or via the telephone.

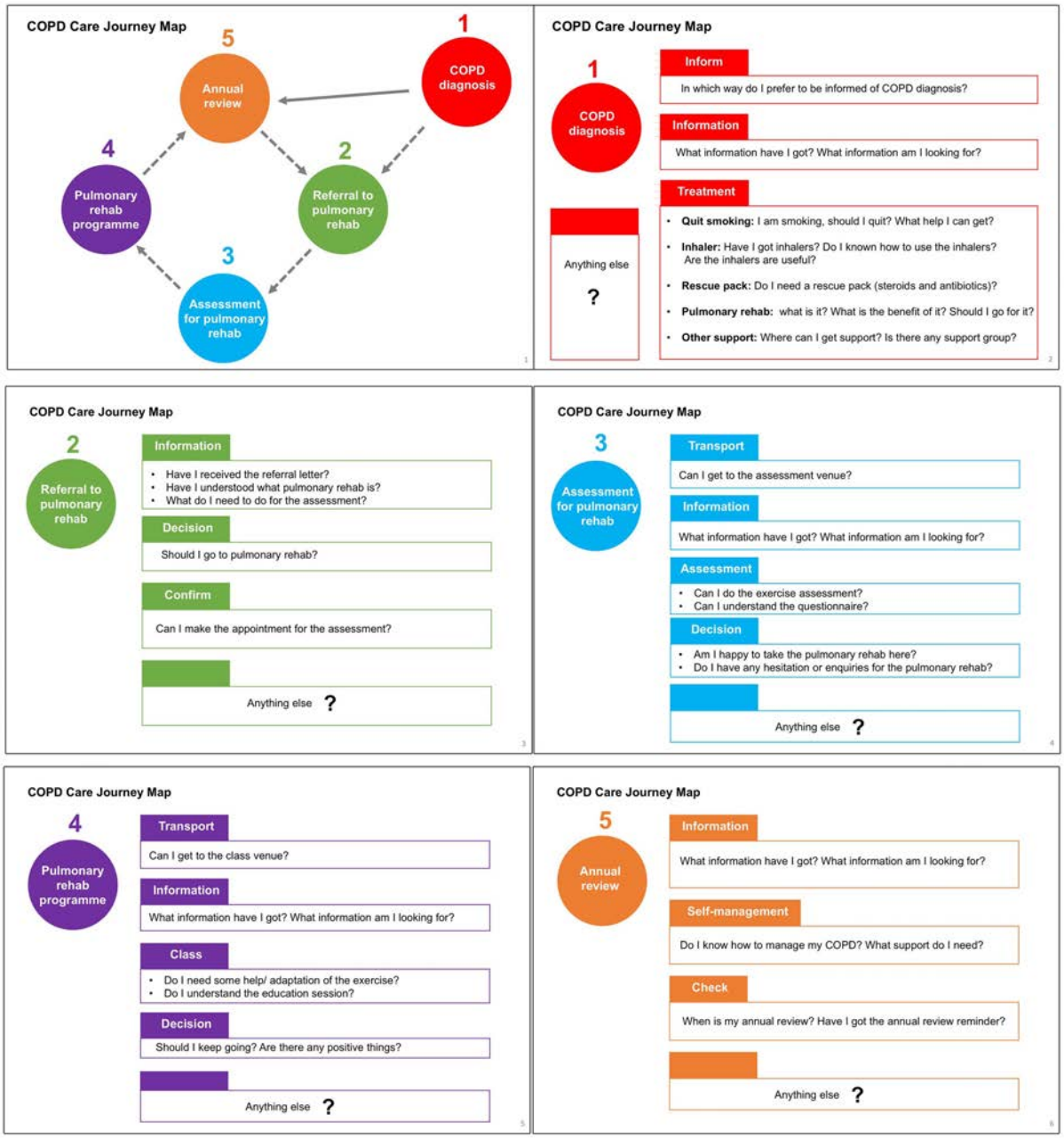
- ☐ Yes. Please leave your contact information_____
- ☐ No

Thank you very much for your time.
A summary of the project will be shared at the end of the study.

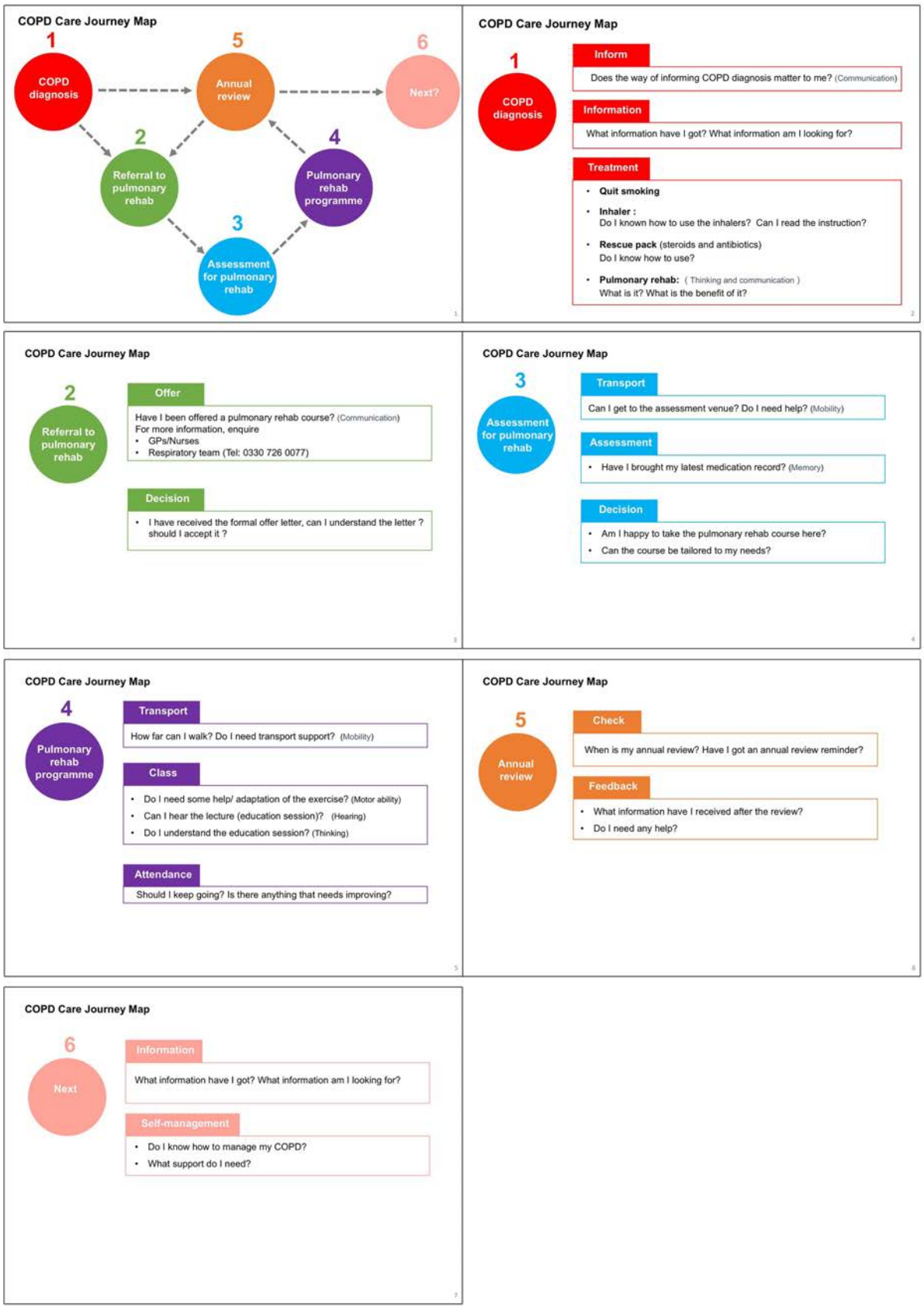
Please feel free to use the following contact information, if you have any questions.
Contact information:
Yuanyuan Liu, Engineering Design Centre, Department of Engineering, University of Cambridge, Trumpington Street, Cambridge, CB2 1PZ
Email: yl528@cam.ac.uk *Tel:* 01223 748 577 or 07922 281 772

2

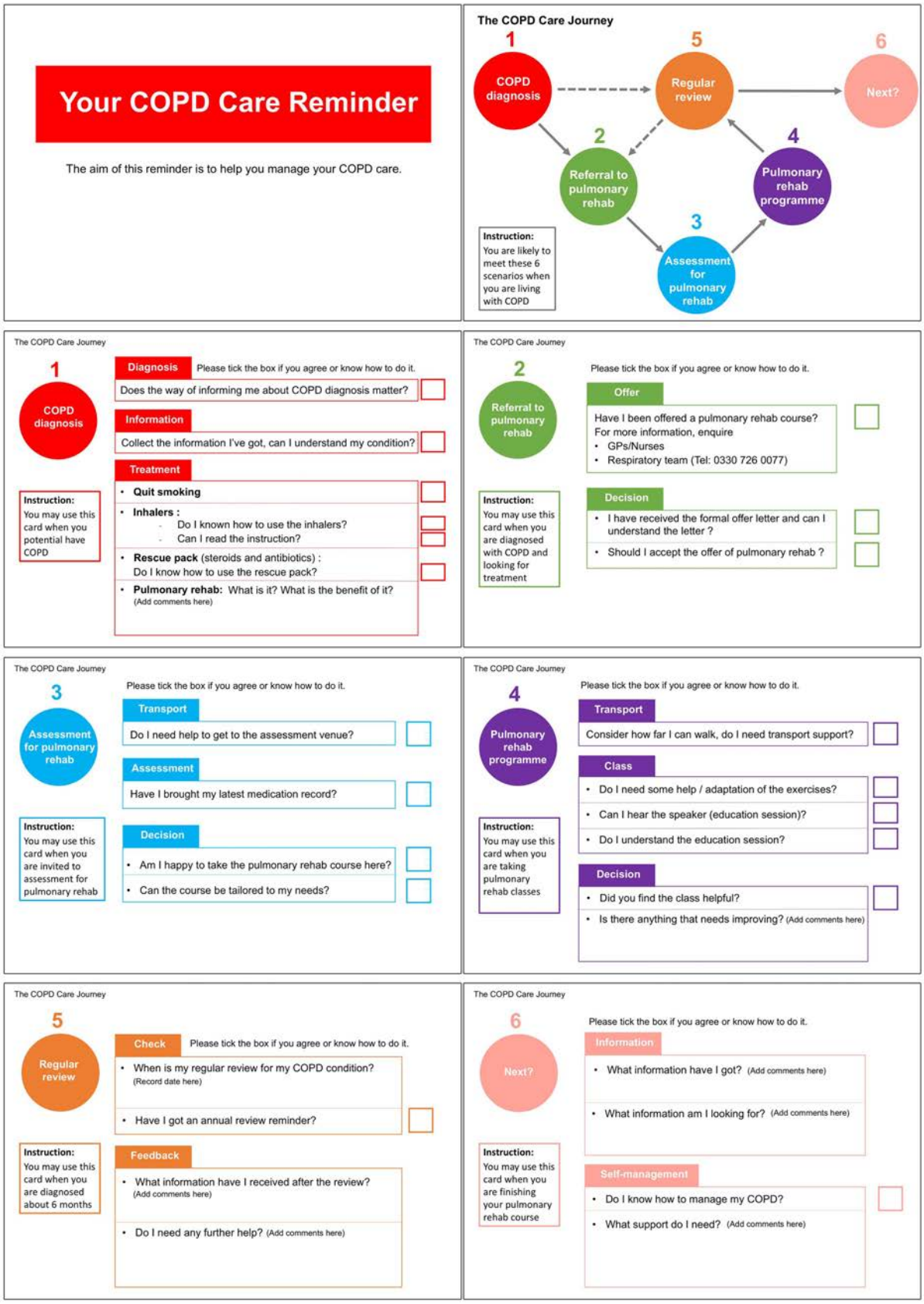
Appendix C20: *Your COPD Care Reminder* V0.1



Appendix C20: *Your COPD Care Reminder* V0.2



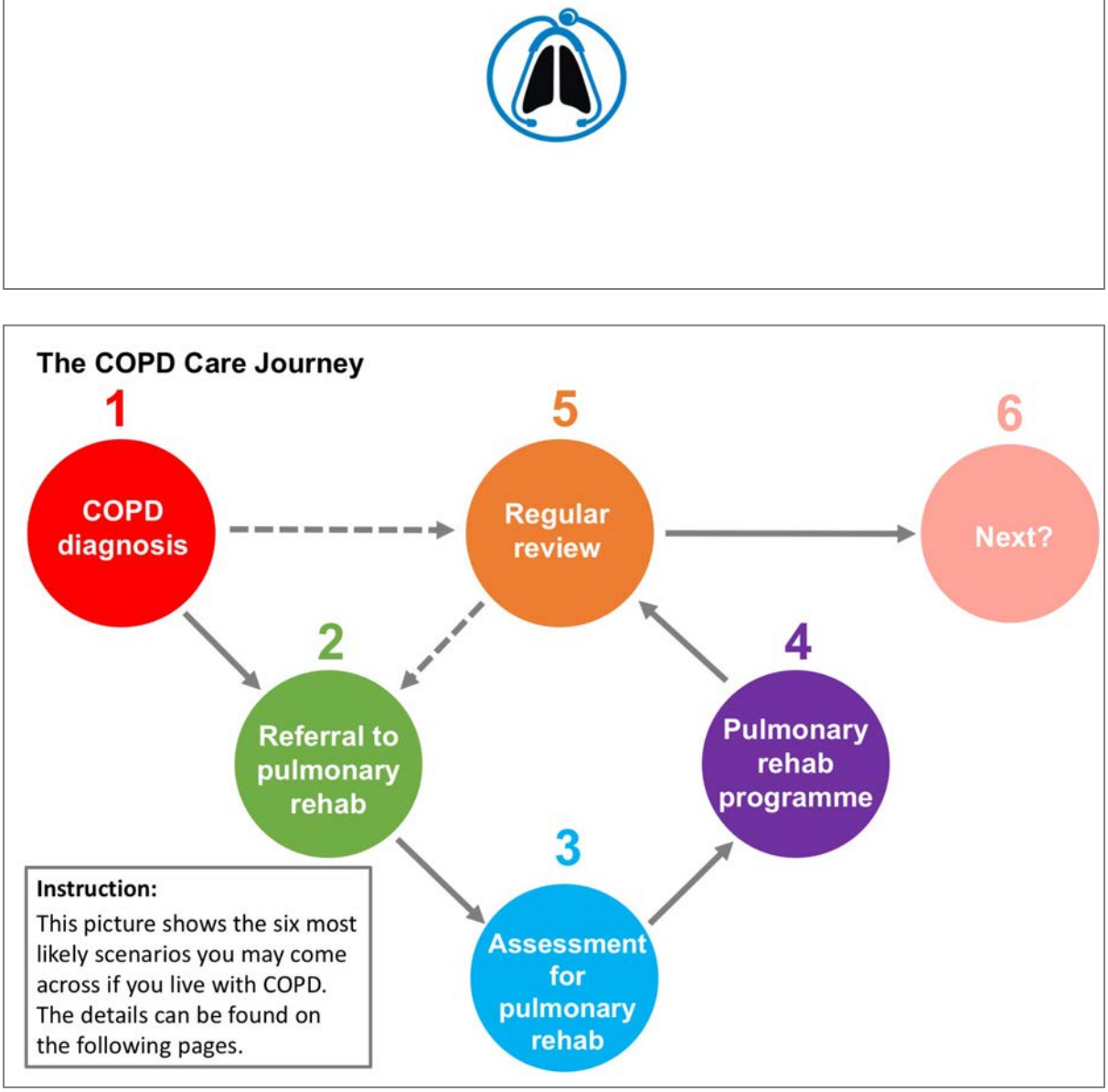
Appendix C20: *Your COPD Care Reminder* V0.3



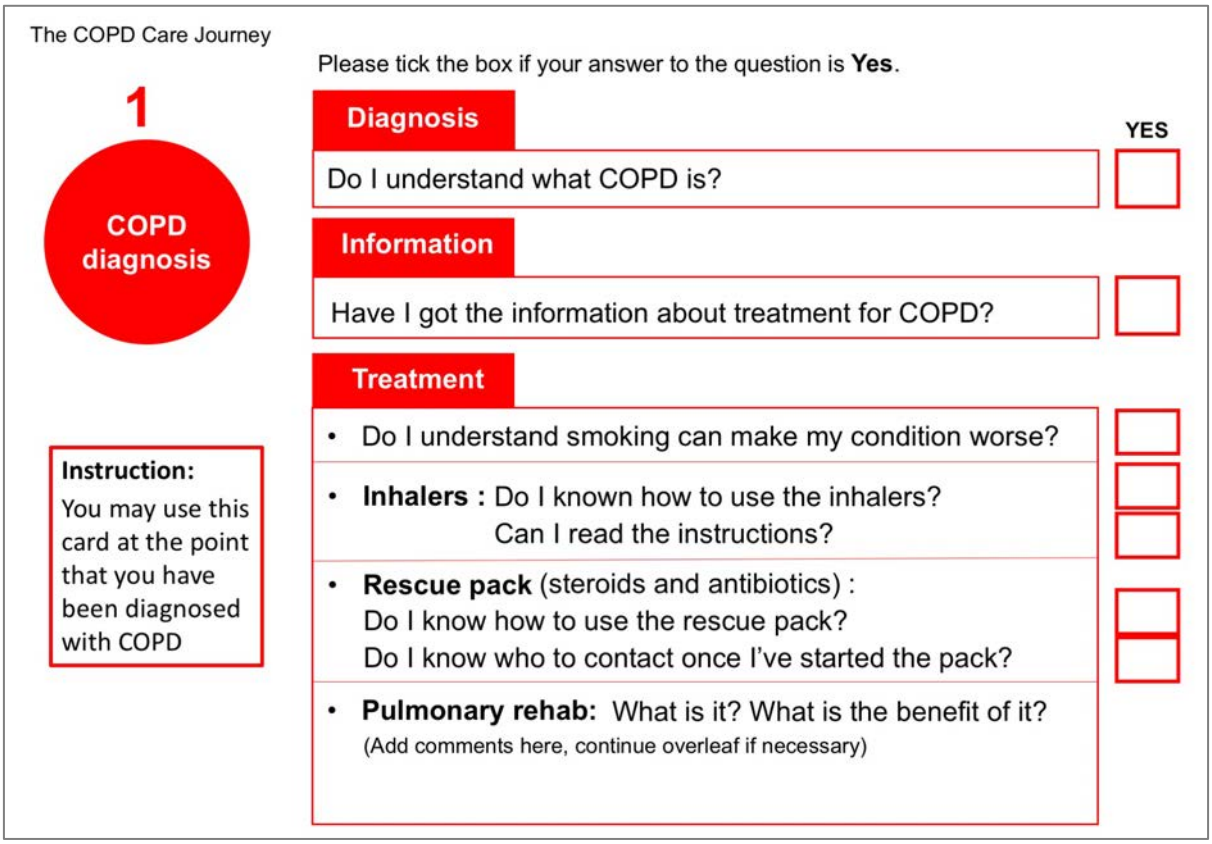
Appendix C20: *Your COPD Care Reminder* final version

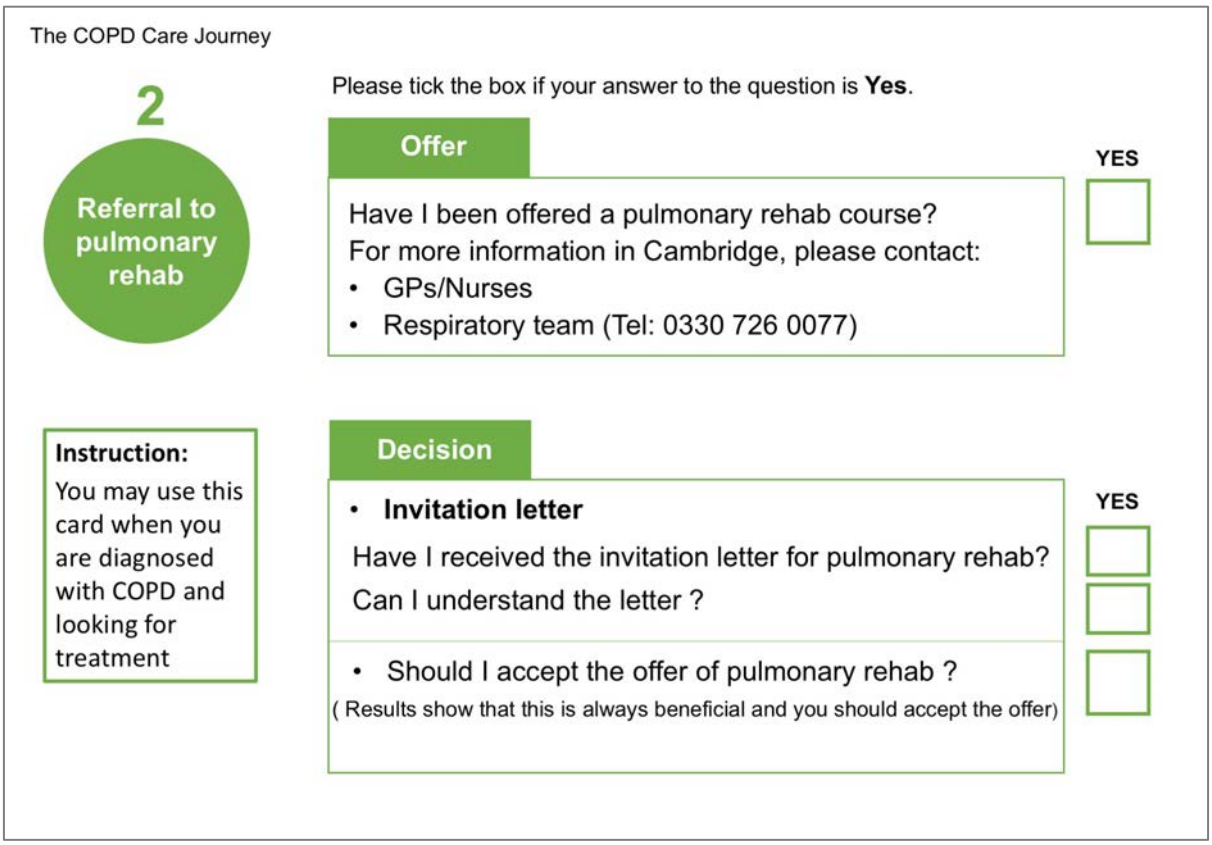
Your COPD Care Reminder

The aim of this reminder is to help you manage your COPD care.

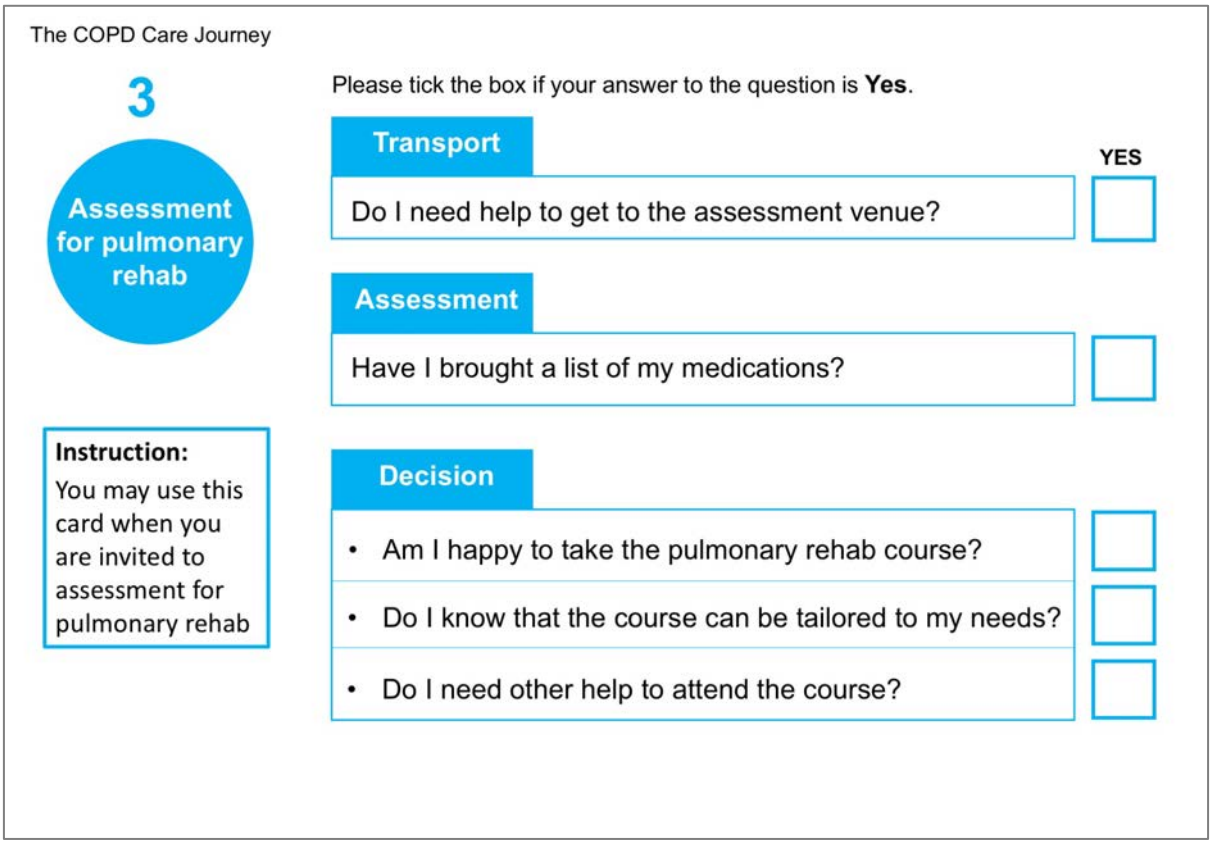


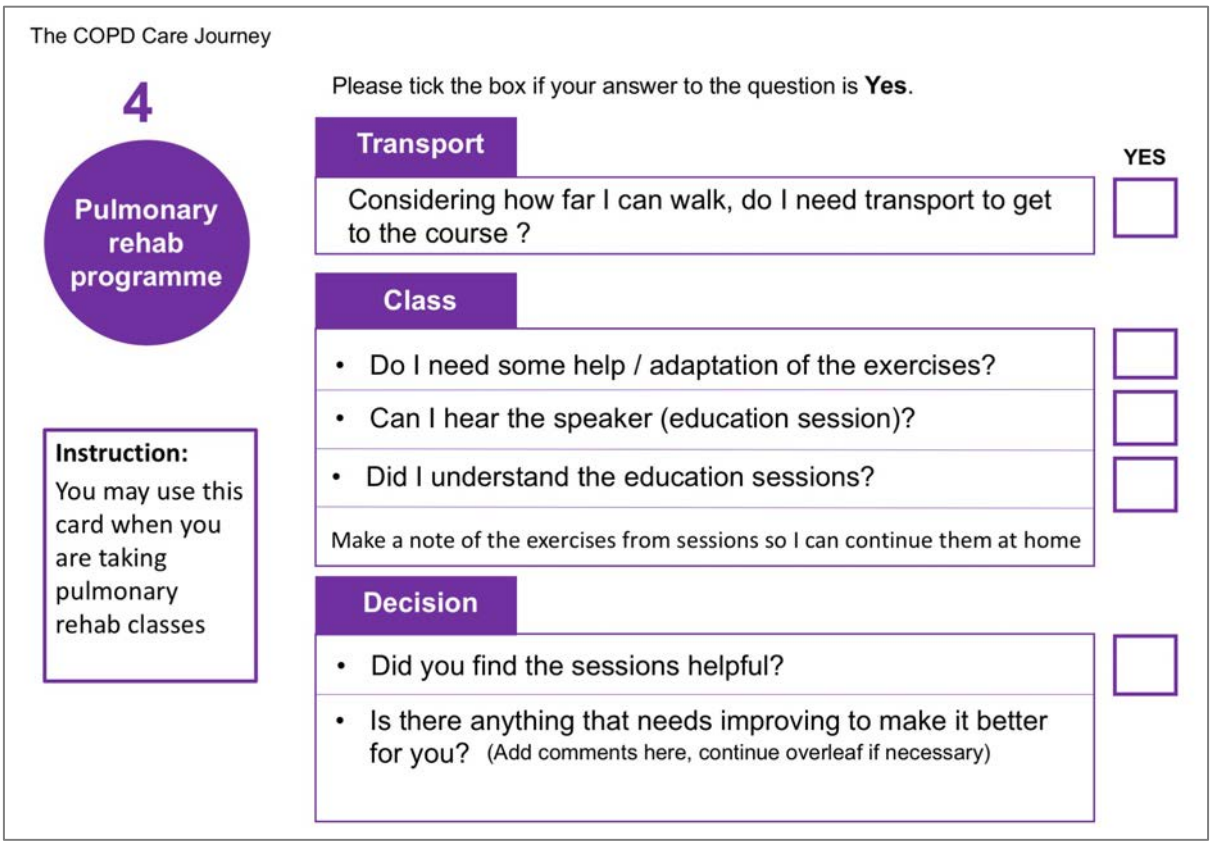
Appendix C20: *Your COPD Care Reminder* final version (continued)





Appendix C20: *Your COPD Care Reminder* final version (continued)





Appendix C20: *Your COPD Care Reminder* final version (continued)